

INTERAGENCY AUTISM COORDINATING COMMITTEE

2010 AUTISM SPECTRUM DISORDER RESEARCH PORTFOLIO ANALYSIS REPORT

Prepared by the Office of Autism Research Coordination
on behalf of the Interagency Autism Coordinating Committee



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OFFICE OF
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CONTENTS

About the IACC	iv
Introduction	1
Who funded ASD research in 2010?	3
<i>IACC Strategic Plan</i> Questions and Corresponding Research Areas	3
Agencies and Organizations Included in the 2010 IACC Portfolio Analysis	4
Federal vs. Private Funding for ASD Research in 2010	5
2010 ASD Research Funding by Agency/Organization	6
What types of ASD research were funded?	7
2010 ASD Research Funding by IACC Strategic Plan Question – All Funders	7
How did the research align with the objectives in the <i>IACC Strategic Plan</i> ?	9
Question 1: Diagnosis	12
Question 2: Biology	14
Question 3: Risk Factors	16
Question 4: Treatments and Interventions	18
Question 5: Services	20
Question 6: Lifespan Issues	22
Question 7: Infrastructure and Surveillance	23
Impact of the American Recovery and Reinvestment Act on Autism Research	25
Impact of ARRA on Total ASD Research Funding in 2009 & 2010	26
Impact of ARRA on Federal ASD Research Funding in 2009 & 2010	26
2009 & 2010 ARRA ASD Research Funding by IACC Strategic Plan Question	28
Impact of 2009 & 2010 ARRA Funding on ASD Research: Alignment with the IACC Strategic Plan	29
Conclusion	30
Appendices	
Appendix A: ASD Research Progress on IACC Strategic Plan Objectives	33
Appendix B: Subcategory Definitions	49
Appendix C: NIH ARRA Initiatives	55
Interagency Autism Coordinating Committee Member Roster	57
Office of Autism Research Coordination Staff Roster	59

About the IACC

The Interagency Autism Coordinating Committee (IACC) is charged with providing advice to the Secretary of Health and Human Services (HHS) and with coordinating all efforts within HHS concerning autism spectrum disorder (ASD). It was established by Congress under the Combating Autism Act of 2006 and renewed under the Combating Autism Reauthorization Act of 2011. Membership of the Committee includes a wide array of Federal agencies involved in ASD research and services, as well as public stakeholders who represent a variety of perspectives from within the autism community. This makeup of the IACC membership is designed to ensure that the Committee is equipped to address the wide range of issues and challenges faced by families and individuals affected by autism.

Under the CAA, the IACC is required to (1) develop and annually update a strategic plan for ASD research, (2) develop and annually update a summary of advances in ASD research, and (3) monitor Federal activities related to ASD.

In completing these tasks, the members of the Committee have worked collaboratively to advance biomedical research and coordinate services that will make an impact for people with ASD and their families.

For more information about the IACC, see www.iacc.hhs.gov.

2010 IACC AUTISM SPECTRUM DISORDER RESEARCH PORTFOLIO ANALYSIS REPORT

INTRODUCTION

In 2011, the Office of Autism Research Coordination (OARC), on behalf of the Interagency Autism Coordinating Committee (IACC), conducted a comprehensive analysis of the 2010 autism spectrum disorder (ASD) research portfolio of major Federal agencies and private organizations. This is the third annual analysis of this nature, following the *2009 IACC Portfolio Analysis Report* released in 2011 and the *2008 IACC Portfolio Analysis Report* released in 2009. The intent of these analyses is to better inform the IACC and interested stakeholders about the funding landscape and current directions for ASD research. Additionally, this analysis examines the extent to which current funding and research topics align with the *2011 IACC Strategic Plan for ASD Research*. The *2010 Portfolio Analysis* can also be used by Federal agencies and private research organizations to help guide future funding priorities by outlining current gaps and opportunities in ASD research, as well as serving to highlight current activities and research progress.

New Features in the 2010 IACC Portfolio Analysis

The *2010 IACC Portfolio Analysis* expands the scope of reporting from prior years by collecting data from five additional funding sources, including four Federal agencies and one private organization. In addition to mapping funded research projects to specific objectives in the *Strategic Plan*, all of the research projects in this analysis have been assigned to a research subcategory that further organizes the projects into groups that share common elements or themes. These subcategories provide a more detailed breakdown of research funding and also help identify the types of research addressed by projects that do not correspond to specific objectives of the *Strategic Plan*.

The 2010 autism research portfolio also includes the final year of funding provided by the American Recovery and Reinvestment Act (ARRA), which increased Federal investments in autism research between 2009 and 2010. An overall analysis of the impact of ARRA funding illustrates how these funds were used to address gaps in the *2011 IACC Strategic Plan for ASD Research*.

In addition to the release of the *2010 IACC Portfolio Analysis Report*, OARC is pleased to release a new online *Autism Spectrum Disorder Portfolio Analysis Web Tool*, which is available on the IACC website (<https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects>). This web tool serves as a companion to the *Portfolio Analysis Report*, providing detailed information on each research project included in the *2009* and *2010 Portfolio Analyses*. The database can be browsed and sorted by several categories, such as "Funder" or "Strategic Plan Question." A search tool enables inquiries based on more specific parameters, such as keywords that may appear in a title or project description. This database will be updated annually with project information from each funder included in the annual *IACC Portfolio Analysis* and can be used by funders, policymakers, researchers, and autism community stakeholders to gather valuable information about ASD research that can support their efforts to serve the autism community.

Who funded ASD research in 2010?

The Office of Autism Research Coordination requested 2010 research project and funding information from 18 Federal agencies and private organizations, including the annual budget for each project and its relevance to the seven critical questions/chapters of the *2011 IACC Strategic Plan for ASD Research*, illustrated below (Figure 1).

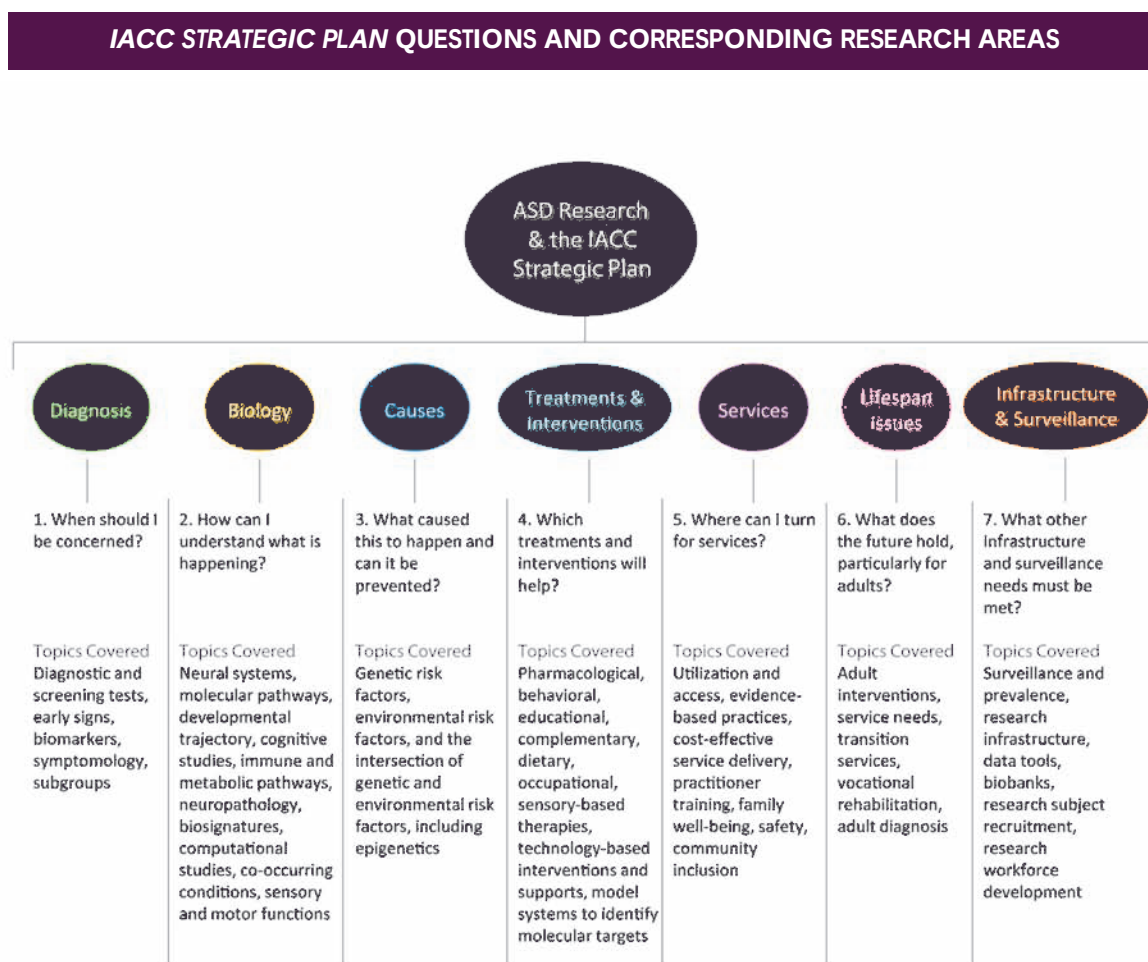


Figure 1. The research areas corresponding to the seven questions of the 2011 IACC Strategic Plan for ASD Research are designated in the oval above each question, and a list of topics covered in each section is listed below each question. The list of topics includes most projects found in each question, but is not necessarily comprehensive.

Table 1 lists the 18 agencies and organizations that participated in this effort. Funders submitting data for the first time in 2010 include the Administration for Children and Families (ACF), the Agency for Healthcare Research and Quality (AHRQ), the Environmental Protection Agency (EPA), the National Science Foundation (NSF), and the Coalition for SafeMinds (SafeMinds). Combined, the estimated Federal and private investment in ASD research in 2010 was \$408,577,276, with the Federal government providing 82% (\$334 million) and private organizations funding 18% (\$74 million) of ASD research (Figure 2). Private investment in ASD research decreased slightly in 2010, compared to about \$78.5 million in 2008 and \$77 million in 2009, possibly reflecting changes in the U.S. economy. The amount of Federal investment in autism research reported in the *2010 Portfolio Analysis* (\$334 million) was significantly larger than the amounts reported in 2008 (\$144 million) and 2009 (\$237 million). This was largely due to the addition of four new Federal funders (ACF, AHRQ, EPA, and NSF), as well as broader reporting of autism-relevant projects from HRSA and the Department of Education. Funding from the American Recovery and Reinvestment Act (ARRA) also continued to bolster the Federal funding of ASD research in 2010. A project count across all funders showed that in 2010, the Federal government supported 932 ASD research projects and private organizations funded 435 projects.

AGENCIES AND ORGANIZATIONS INCLUDED IN THE 2010 IACC PORTFOLIO ANALYSIS

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
Administration for Children and Families (ACF)	Autism Research Institute (ARI)
Agency for Healthcare Research and Quality (AHRQ)	Autism Science Foundation (ASF)
Centers for Disease Control and Prevention (CDC)	Autism Speaks (AS)
Centers for Medicare & Medicaid Services (CMS)	Center for Autism and Related Disorders (CARD)
Department of Defense (DoD)	Coalition for SafeMinds (SafeMinds)
Department of Education (ED)	Organization for Autism Research (OAR)
Environmental Protection Agency (EPA)	Simons Foundation (SF)
Health Resources and Services Administration (HRSA)	Southwest Autism Research & Resource Center (SARRC)
National Institutes of Health (NIH)	
National Science Foundation (NSF)	

Table 1. The table lists the ten Federal agencies and eight private organizations included in the 2010 IACC Autism Spectrum Disorder Research Portfolio Analysis of ASD research funding.

What was the breakdown of funding?

The 18 stakeholders that were included in this analysis contributed a total of \$408,577,276 across 1,367 ASD research projects in 2010 (Table 2). This should be considered an estimated total funding amount because some funders provided estimated annual funding data.

The National Institutes of Health (NIH) was the leading contributor of funding for ASD research in 2010 with a total of \$217 million funding 545 projects. This amount included \$58 million in ARRA funding and \$160 million in non-ARRA funding (funding provided by the annual NIH appropriation). The NIH non-ARRA funding represented an increase from the corresponding 2009 non-ARRA funding level of \$132 million. The Simons Foundation and Autism Speaks were the largest private funders of ASD research in 2010, with investments of more than \$53 million and \$18 million, respectively. The next largest Federal funders were the Health Resources and Services Administration (HRSA) (\$43 million) and the Department of Education (\$30 million).

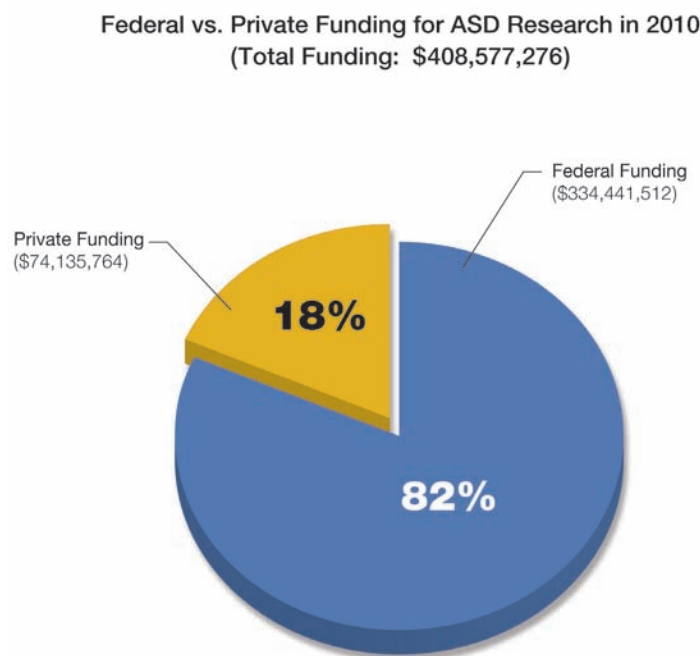


Figure 2. Eighty-two percent of the \$408,577,276 distributed for ASD research in 2010 was provided by Federal sources, while 18% of funding was provided by private organizations.

The number of projects and amount of funding in the *Portfolio Analysis* were substantially higher in 2010 compared to 2009 (\$314 million over 995 projects in 2009 compared to \$408 million over 1,367 projects in 2010). This was largely attributed to the addition of new funders in the present analysis as well as more comprehensive data collection from some previously represented funders. However, many funders participating in the previous analysis also increased their investment levels between 2009 and 2010.

2010 ASD RESEARCH FUNDING BY AGENCY/ORGANIZATION		
Funding Agency/Organization	Number of Projects	Total Funding
National Institutes of Health (NIH)	545**	\$217,143,701
Simons Foundation (SF)	123	\$53,729,921
Health Resources and Services Administration (HRSA)	82	\$43,303,150
Department of Education (ED)	139	\$30,432,564*
Centers for Disease Control and Prevention (CDC)	30	\$19,698,859
Autism Speaks (AS)	228	\$18,476,890
National Science Foundation (NSF)	69	\$12,222,206*
Department of Defense (DoD)	58	\$7,082,059
Administration for Children and Families (ACF)	1	\$1,877,959
Agency for Healthcare Research and Quality (AHRQ)	4	\$1,548,053*
Center for Autism and Related Disorders (CARD)	31	\$906,482
Environmental Protection Agency (EPA)	1	\$756,802
Autism Research Institute (ARI)	15	\$386,905
Centers for Medicare & Medicaid Services (CMS)	3	\$376,159
Autism Science Foundation (ASF)	13	\$245,000
Organization for Autism Research (OAR)	12	\$191,590
Coalition for SafeMinds (SafeMinds)	8	\$128,975
Southwest Autism Research & Resources Center (SARRC)	5	\$70,000
GRAND TOTAL	1367	\$408,577,276

*Annual funding amounts for AHRQ, ED, and NSF are estimated.

**The NIH project number shown reflects unique NIH projects. Projects funded by more than one NIH institute ("co-funds") were combined and only counted as a single project. This approach differs from that used in the NIH RePORT database, where each co-fund is counted as a separate project when the data are exported into Excel.

Table 2. The table lists the total funding provided by the 18 Federal agencies and private organizations included in the *Portfolio Analysis* and the number of projects funded. Please note that the NIH budget figure includes both ARRA (\$58 million) and non-ARRA (\$160 million) funding. Together, the agencies and organizations funded 1367 projects in 2010, representing an overall investment of more than \$408 million.

What types of ASD research were funded?

To better understand what areas of research were funded in 2010, projects were aligned with the corresponding questions in the *2011 IACC Strategic Plan*. Figure 3 illustrates the breakdown of the research funding according to the *Strategic Plan*'s seven questions related to diagnosis, biology, risk factors, treatments and interventions, services, lifespan issues, and infrastructure and surveillance. Identifying how current research investments correspond to the *Strategic Plan* provides an understanding of how funders have directed investments across each of the priority areas identified by the IACC, as well as an indication of which areas are well supported versus those that may be in need of additional attention or development.

2010 ASD Research Funding by IACC Strategic Plan Question – All Funders
(Total Funding: \$408,577,276)

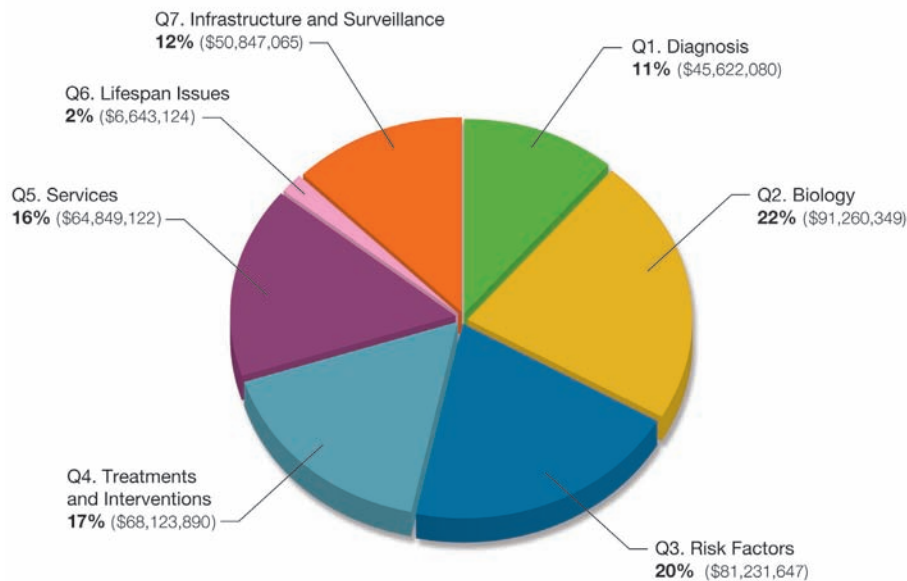


Figure 3. Topic areas are defined by each question in the IACC Strategic Plan. The seven questions of the Strategic Plan are represented in the clockwise direction, beginning with Diagnosis (Question 1) and ending with Infrastructure and Surveillance (Question 7). In 2010, the largest proportion of ASD research funding was devoted to understanding the underlying biology of ASD (Question 2; 22%); 20% of the research was related to identifying risk factors for ASD (Question 3); 17% addressed treatments and interventions (Question 4); 16% related to services (Question 5); 12% covered scientific infrastructure and surveillance (Question 7), and 11% related to diagnosis (Question 1). Research on lifespan issues (Question 6) received 2% of the total funding provided.

As in previous years, 2010 ASD research funding supported projects relevant to all critical questions in the *Strategic Plan*. The largest portion of funding addressed the underlying biology of ASD (22%; Question 2), followed closely by identifying potential causes and risk factors for the disorder (20%; Question 3). Treatments and interventions for ASD, including behavioral therapy, classroom interventions, pharmacological treatments, and dietary interventions, accounted for 17% of ASD research funding in 2010. The greatest increase in proportion of funding was in the services section of the *Strategic Plan* (Question 5), which grew from 3% in 2009 to 16% in 2010. Much of this increase was attributed to additional projects reported by the Health Resources and Services Administration (HRSA), largely related to practitioner training. The next largest category of funding was scientific research infrastructure (12%; Question 7). This includes data repositories such as the National Database for Autism Research (NDAR) and the Autism Genetics Resource Exchange (AGRE), as well as surveillance, including studies of ASD prevalence conducted by the Centers for Disease Control and Prevention (CDC). Research on autism screening and diagnosis accounted for 11% of ASD funding in 2010, with nearly the same amount of funding as 2009.

Overall, 2010 ASD research funding was more evenly distributed among the questions of the *Strategic Plan* than in previous years. This change in distribution is partially due to more comprehensive reporting of ASD projects by Federal services agencies, which increased services funding (Question 5) to levels comparable to other areas. Although lifespan issues funding (Question 6) is proportionally smaller than the other areas, the funding for this question increased more than four-fold from 2009 levels. The IACC highlighted this as an area of needed growth, and funders have responded to this emerging area that merges services needs through the lifespan with new scientific research on the how the aging process affects individuals with autism.

How did the research align with the objectives in the *IACC Strategic Plan*?

Within the seven questions that serve as the framework for the *IACC Strategic Plan*, each question has several specific short- and long-term objectives. The objectives in the *Strategic Plan* call for specific research efforts with a goal date for completion and include an estimate of the budget required to accomplish the goal.¹ Each ASD project that received funding in 2010 was evaluated to determine which question and objective it fulfilled. This enabled assessment of progress corresponding to the *Strategic Plan* and identification of gaps in funded research.

In total, there are 78 objectives in the *2011 IACC Strategic Plan*, including 16 newly added objectives addressing a range of research areas such as bioinformatic approaches to address environmental risk factors for ASD, studies of the microbiome, the role of epigenetics, microarray testing for genetic risk factors, studies focusing on interventions for nonverbal individuals with autism, safety issues, dental health issues, health promotion, ethical implications of research, and objectives to promote more data infrastructure and to enhance networks of clinical care. Based on the 2010 funding data, significant progress has been made toward fulfilling the objectives in the *2011 Strategic Plan*, with at least some progress on 83% of the objectives. Only 13 of the objectives do not have any projects or funding directed to those particular research areas.

The following sections will give an overview of the progress on fulfilling objectives in each question of the *Strategic Plan*. The overall progress for each question will be denoted by a stoplight figure, with the number of objectives that are fully or partially fulfilled indicated in the green or yellow light (respectively), and the number of objectives where no progress has been made indicated in the red light. Within each question (1 to 7), the objectives are set apart by designating them as short- or long-term (with an “S” or an “L”), followed by sequential letters of the alphabet (e.g., 2.S.A, 2.S.B, 2.L.A, 2.L.B). For clarity of discussion, these shorthand abbreviations will be used in this analysis. For example, the first short-term objective in Question 1 is referred to as 1.S.A. Full titles and funding information for each objective, as well as the progress designated by the green, yellow, or red coding, can be found in Appendix A.

¹ Budget recommendations were formulated by scientific and program experts in the field and provide an estimate of what it would cost to conduct each project. The IACC provides these budget recommendations as guidance to Federal agencies and partner organizations on the potential cost of conducting the recommended research. The IACC’s role in research is advisory, and the Committee does not have its own research budget to conduct or support research.

While attempts were made to assign all projects in the *Portfolio Analysis* to a specific objective, some projects could only be assigned at the Question level. This may be because they lacked particular aspects of research design required by the objective or because that type of research was not identified as a gap area in the *Strategic Plan*. In 2010, every question of the *Strategic Plan* included projects that were not specific to a particular objective (Figure 4). In particular, Question 2 (Biology) has a significant proportion of projects (60%) that are not specific to any *Strategic Plan* research objectives. The subcategory classification system, new to the 2010 *Portfolio Analysis*, was developed to help the IACC and other readers of this report to understand what types of research are encompassed by projects that do not fall into particular research objectives within the *Strategic Plan*.

2010 ASD Funding: Alignment with IACC Strategic Plan Objectives

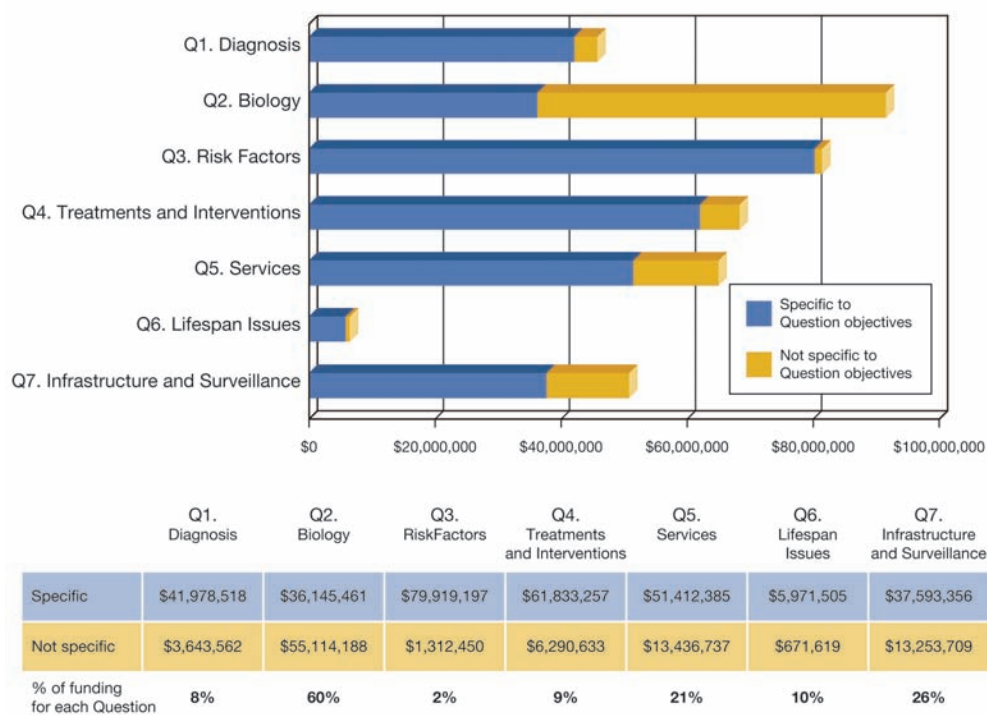


Figure 4. Each question in the *Strategic Plan* contained projects that were not specific to a particular objective. Funding for projects that fall under specific objectives are indicated in blue and projects that are not specific to objectives within a question are indicated in yellow. In 2010, the questions with the most projects that were not specific to their respective objectives were Question 2 (60%), Question 7 (26%), and Question 5 (21%). Questions 1, 4, and 6 all had similar proportions of funding for projects not specific to objectives (8%, 9%, and 10%, respectively). Question 3 had the smallest proportion of projects not specific to objectives, with just 2%. Subcategory analysis provided within the summary for each question of the *Strategic Plan* provides description of the topic areas addressed by all projects, including those that are not specific to IACC *Strategic Plan* objectives.

The subcategory analysis assesses the autism research projects based on the types of research conducted in each question of the *Strategic Plan* (Diagnosis, Biology, Risk Factors, Treatments and Interventions, Services, Lifespan Issues, Infrastructure and Surveillance). While some of the projects in the *Portfolio Analysis* do not fall within the specifications of a particular objective, the subcategories facilitate a comprehensive description of all of the research within a particular question.

For this analysis, subcategories were generated for each *Strategic Plan* question to provide a more comprehensive and detailed categorization of the research. Each project in the *2010 Portfolio Analysis* data was then assigned to a subcategory based on the research area it addressed. For example, within Question 1 (Diagnosis), the projects were divided into four subcategories: Diagnostic and screening tools, Early signs and biomarkers, Intermediate phenotypes/Subgroups, and Symptomology. Projects were assigned to the one subcategory that corresponded best to the research aims. In addition to describing autism research, this categorization system also captured the types of research that did not fall within specific objectives of the *Strategic Plan*. A complete list of the subcategories used for each question can be found in Appendix B, along with descriptions of the types of research in each classification.

Question 1: Diagnosis

Projects assigned to Question 1 (“When Should I Be Concerned?”) of the *Strategic Plan* comprised eleven percent (\$45.6 million) of 2010 total ASD funding. Progress on the nine objectives in Question 1 is indicated by the stoplight figure to the right. In 2010, six objectives fulfilled their recommended budget amount (green light), while no progress was made on three objectives (red light). As in 2009, the two objectives receiving the most funding included developing measures to identify subtypes across the autism spectrum (1.L.B, 33%) and projects to discover biomarkers for ASD (1.L.A, 29%). A full list of objectives and their progress can be found in Appendix A. Eight percent of funding for Question 1 went to projects that were not specific to Question 1 objectives (Figure 4).



Two new objectives were added to Question 1 in 2011: one to determine the potential value of microarrays to use in genetic testing related to diagnosis (1.S.E) and another that called for a workshop to address the ethical, legal, and social implications (ELSI) of ASD research (1.S.F). While a few projects in the *2010 Portfolio Analysis* related to the use of microarrays, an ELSI workshop was not held in 2010, so that objective was left incomplete in this analysis. However, an ELSI

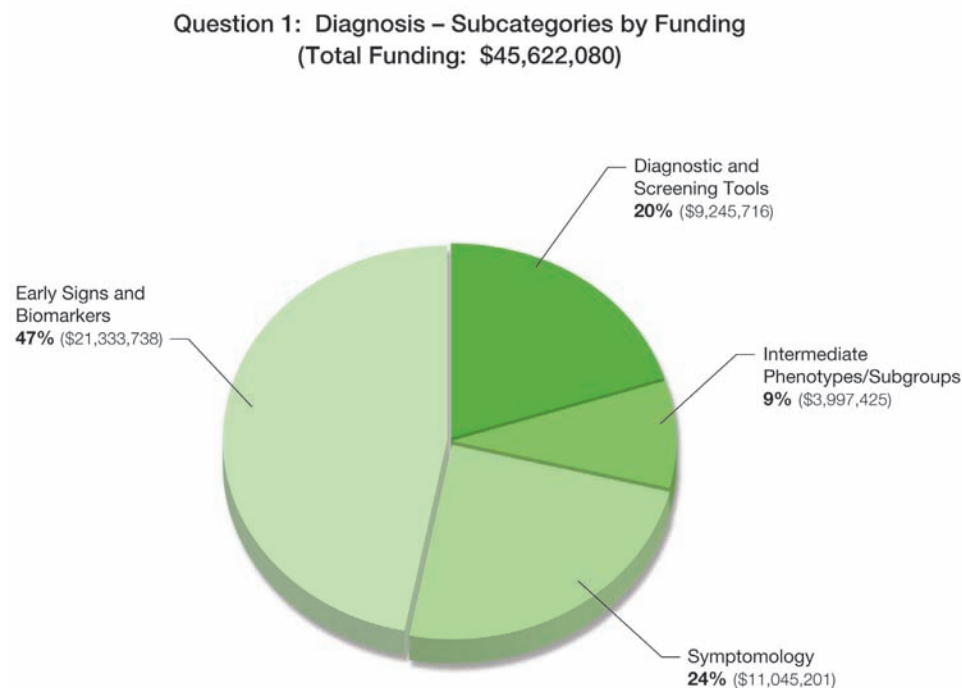


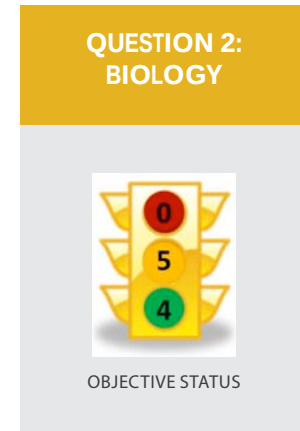
Figure 5. The four subcategories for research related to Question 1 (Diagnosis) illustrated a heavy focus on identifying Early signs and biomarkers for ASD. Characterizing Symptomology and developing Diagnostic and screening tools also received significant funding (24% and 20%, respectively). The smallest subcategory focused on identifying Intermediate phenotypes and subgroups of people with ASD (9%).

workshop was planned and held in 2011, and fulfillment of this objective will be reflected in the *2011 Portfolio Analysis*. Other objectives in Question 1 that still need attention include studies to understand the impact of early diagnosis on choice of intervention and outcomes (1.S.D) as well as studies to identify reasons for health disparities in accessing early screening and diagnosis services (1.S.C).

With the development of the subcategory categorization approach, projects that did not fit within research objectives are now classified, enabling better understanding of the research areas addressed by these projects. The research projects in Question 1 were divided into four subcategories: Diagnostic and screening tools, Early signs and biomarkers, Intermediate phenotypes/Subgroups, and Symptomology (Figure 5). Of the 166 projects in Question 1, 47% focused on looking for Early signs and biomarkers of ASD. These studies included eye tracking, infant and toddler development (often comparing children with ASD to their unaffected siblings or to typically developing children), and identifying differences in emotional or social interaction. The search for biomarkers of ASD encompassed both biological and behavioral markers of the disorder. Research evaluating and defining the Symptomology of ASD comprised 24% of the funding for Question 1 projects, and the development of new diagnostic, screening, and assessment tools accounted for 20% of Question 1 funding. The smallest subcategory of funding (9%) addressed defining Intermediate phenotypes and subgroups in individuals with ASD.

Question 2: Biology

Question 2 (“How Can I Understand What is Happening?”) addresses the underlying biology of ASD and accounted for the most ASD research funding in 2010 (22%; \$91 million). At least some progress was charted for each of the nine objectives in this question. Five of the objectives were partially fulfilled (yellow light in the stoplight figure to the right) while the other four objectives met the budget recommendations in their respective research areas (green light). Sixty percent of funding for Question 2 did not fit into a specific objective (Figure 4), and no new objectives were added to Question 2 in the 2011 Strategic Plan.



A significant portion of funding in this question (14%; \$13 million) was devoted to understanding the underlying biology of genetic conditions related to ASD, including fragile X syndrome, Rett syndrome, and tuberous sclerosis complex (2.S.D). Projects that aimed to associate a specific genotype with a functional or structural phenotype, such as whether individuals with a specific gene variant tend to have increased social impairment compared to those who have other genotypes, received 10% (\$9 million) of funding in Question 2 (2.S.G). These two objectives also

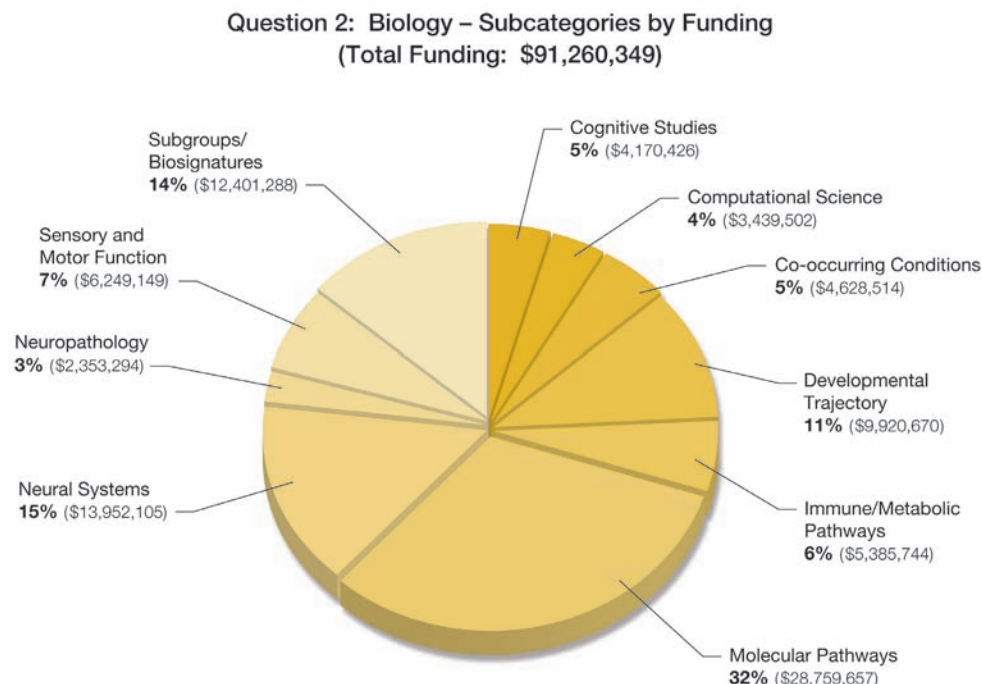


Figure 6. Question 2 encompassed a broad range of biological research, resulting in the need to create a larger number of subcategories to adequately describe the breadth of research than was required for other Strategic Plan Questions. The subcategory with the largest portion of funding was Molecular pathways (32%), followed by Neural systems and Subgroups/Biosignatures, which each received less than half the funding of Molecular pathways (15% and 14%, respectively). Projects related to Developmental trajectory were supported by 11% of 2010 ASD research funding, and research on Sensory and motor function received 7%. Studies on Immune/Metabolic pathways (6%), Co-occurring conditions (5%), Cognitive studies (5%), and Computational science (4%) round out the types of research in Question 2.

received the largest portion of Question 2 funding in the *2009 Portfolio Analysis*. Four of the objectives in Question 2 received 1% or less of the recommended amount of funding in 2010 (2.S.B, 2.S.C, 2.S.F, and 2.L.B); these same objectives also received very little funding in 2009.

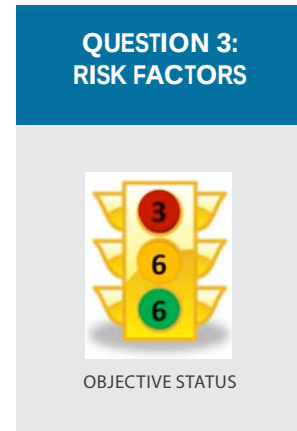
While all objectives in Question 2 had some measurable research progress, the majority of research projects in this question did not fall under a particular objective. These projects were classified as “2 Other,” and they accounted for 60% of the funding (\$55 million) in Question 2 in the *2010 Portfolio Analysis*. This was comparable to the *2009 Portfolio Analysis*, when the funding for these “2 Other” projects corresponded to 54% of the total funding for Question 2. The large number of projects in this category may be related in part to the substantial amount of research on the underlying biology of ASD that was ongoing prior to the development of the *IACC Strategic Plan*. When the IACC developed the *Strategic Plan*, they intentionally focused the *Plan’s* research objectives on gap areas, which left many well-funded areas of research unspecified in the list of objectives within the *Strategic Plan*.

Question 2 contained more projects (409 projects; 30%) than any other question in the *Strategic Plan* and includes a broad range of biological research, from neural connectivity and imaging studies to sensory processing to cellular and animal models used to explore the molecular biology of ASD. Thus, this question was also divided into the largest number of subcategories assigned to any single question. These include: Cognitive studies, Computational science, Co-occurring conditions, Developmental trajectory, Immune/Metabolic pathways, Molecular pathways, Neural systems, Neuropathology, Sensory and motor function, and Subgroups/Biosignatures (Figure 6).

The largest portion of funding by far (32%; nearly \$29 million) was devoted to research on Molecular pathways (systems of genes, proteins, and other molecules) involved in ASD and related disorders (such as fragile X, Rett syndrome, etc.), including projects that explore the function of these pathways using animal model systems that mimic various aspects of ASD. Research exploring the Neural systems involved in ASD, including brain structure and neural circuitry, as well as projects identifying ASD Subgroups and biosignatures, each accounted for about 15% of Question 2. These studies frequently employed imaging techniques such as fMRI (functional magnetic resonance imaging) to explore neural connections, often relating them to behavior or physical traits. Longitudinal studies that follow social, behavioral, and physical development over time comprised 11% of funding (Developmental trajectory subcategory), and research specific to Sensory and motor function corresponded to 7% of the funding. Research on the mechanisms of Immune and metabolic pathways accounted for 6% of ASD funding in 2010. Co-occurring conditions (including sleep disorders, epilepsy, and familial autoimmune disorders), Cognitive studies, and Computational science each accounted for about 5% of funding in Question 2.

Question 3: Risk Factors

Question 3 (“What Caused This to Happen and Can It Be Prevented?”) received 20% (\$81 million) of the total funding for ASD research in 2010. Of the fifteen objectives in this question, six of them were partially fulfilled (yellow light in the stoplight figure to the right) and six reached the recommended funding level (green light). Nearly all projects in Question 3 were assigned to a particular objective, with only 2% of the funding distributed to projects that were not specific to the question objectives (Figure 4). The objective that received the largest proportion of funding in 2010 (42%, \$34 million) focused on identifying genetic risk factors for ASD (3.L.B), followed by more than \$16 million (21%) for the objective for genome-wide association studies to find candidate genes for autism (3.S.A).



Five Question 3 objectives were new to the 2010 analysis. These new objectives included research on epigenetics (3.S.J), investigating differences in the microbiome of individuals with ASD (3.S.I), developing model systems to explore environmental risks and their interaction with gender and genetic susceptibilities (3.S.K), studying special populations to understand environmental risk factors (3.S.H), and convening a workshop to assess the usefulness of bioinformatic approaches to identify environmental risks (3.S.G).

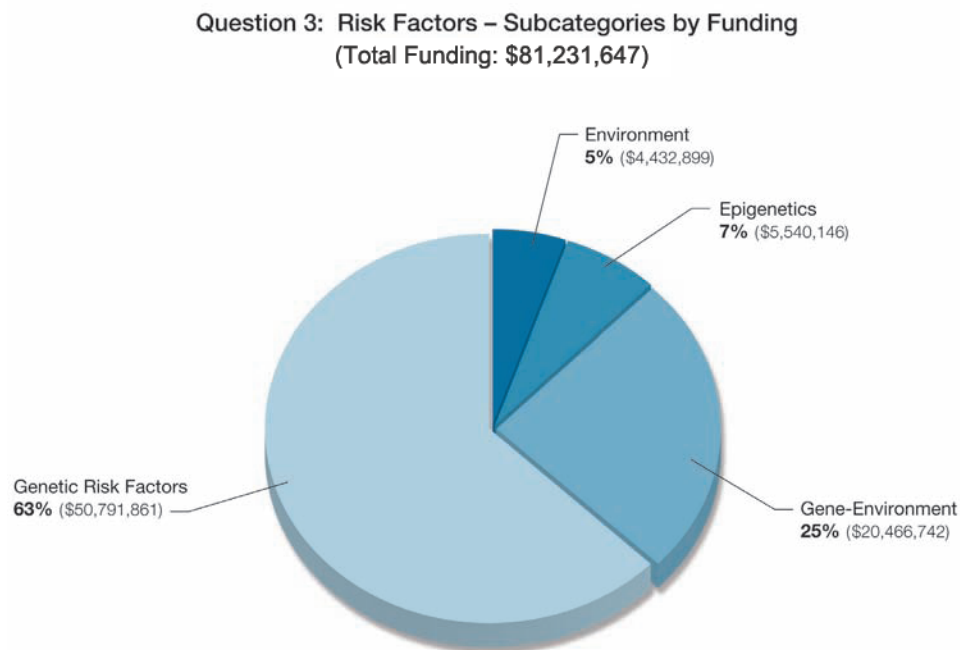


Figure 7. Genetic risk factors accounted for a majority of research funding in Question 3 in 2010 (63%). Gene-Environment studies received 25% of funding, Epigenetic studies 7%, and Environment studies 5%.

Three of the objectives in Question 3 received a red light, indicating no progress in 2010. One of these objectives seeks to develop measures for identifying markers of environmental exposure in biospecimens (3.S.B), and another strives to ensure that racially and ethnically diverse populations affected by ASD are enrolled in research studies (3.S.D). The other unfulfilled objective involves organizing a workshop to explore bioinformatic approaches to identify environmental risks (3.S.G). While this workshop was not convened in 2010 (and is considered red, or no progress in this report), a workshop on this topic was held in 2011 and completion of this objective will be reflected in the next *Portfolio Analysis Report*.

Projects in Question 3 were divided into four main subcategories: Environment, Epigenetics, Gene-Environment, and Genetic risk factors (Figure 7). Epigenetics is the study of heritable changes in gene function that occur without a change in the DNA sequence (such as methylation of DNA, which can influence whether genes are “turned on” or “turned off” in specific tissues during various points in development). These changes can be caused by environmental factors. Gene-Environment research investigates environmental risk factors in the presence of genetic susceptibility. Thus, these latter two subcategories include strong environmental components as well as genetic aspects. Genetic risk factors accounted for 63% of funding in 2010 based on the subcategory analysis. Projects that considered only environmental factors accounted for 5% of funding, while projects that examined Gene-Environment interactions accounted for 25%. Epigenetics received 7% of the ASD research funding in Question 3. Combined, all of the subcategories in Question 3 that may take environmental factors into account (Environment, Gene-Environment, and Epigenetics) represented 37% of the Question 3 funding landscape.

Question 4: Treatments and Interventions

Research addressing Question 4 (“Which Treatments and Interventions Will Help?”) received 17% of 2010 ASD research funding (\$68 million). Overall progress on the objectives in this question is illustrated in the stoplight figure to the right, with fulfillment of funding goals on five objectives (green light), partial fulfillment of six objectives (yellow light), and no progress on one objective (red light). Nine percent of the funding in Question 4 went to projects that were not specific to an objective within that question (Figure 4).

QUESTION 4: TREATMENTS AND INTERVENTIONS



OBJECTIVE STATUS

One objective in Question 4 progressed from yellow to green light status between 2009 and 2010. This objective calls for studies to evaluate the safety and effectiveness of medications commonly used to treat co-occurring conditions or specific behavioral issues in people with ASD (4.L.C). The Question 4 objective to develop model systems that replicate features of ASD received the highest proportion of funding in both 2009 and 2010 (4.S.B, 34% in 2010).

Question 4: Treatments and Interventions – Subcategories by Funding
(Total Funding: \$68,123,890)

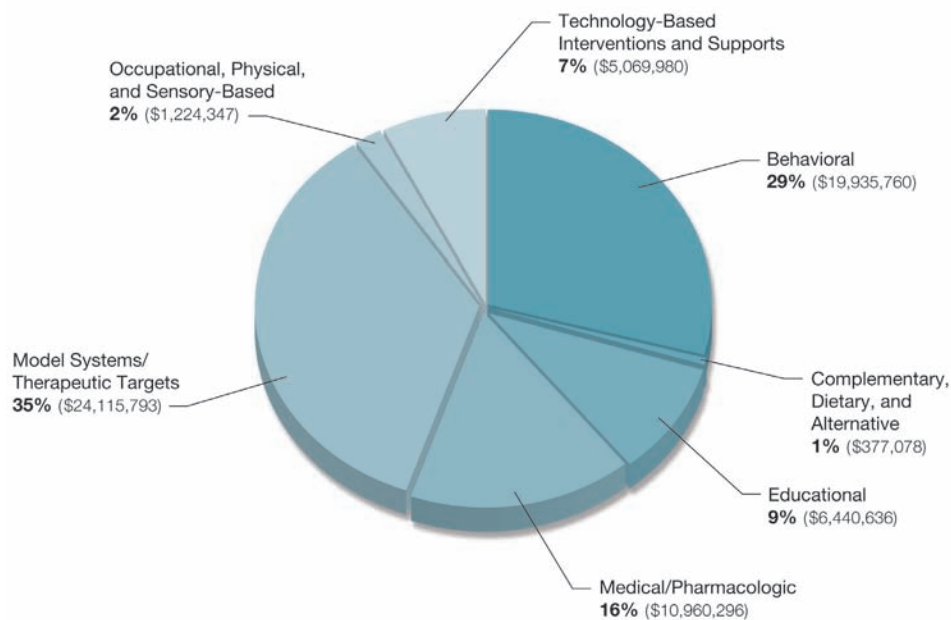


Figure 8. The subcategories for Question 4 illustrate the many approaches to treatments and interventions supported by autism research funders. The largest amount of funding supported projects to develop Model systems and therapeutic targets (35%), followed by research on Behavioral interventions (29%). Medical/Pharmacologic interventions received 16% of funding, classroom-based interventions (Educational) received 10% of funding, and Technology-based interventions and supports received 7% of funding. The subcategories with the smallest amounts of funding included Occupational, physical, and sensory-based (2%) and Complementary, dietary, and alternative (1%).

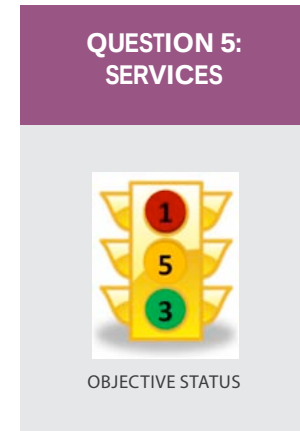
Of the twelve objectives in Question 4, three were new to this analysis. The new objectives ranged from studies on interventions for nonverbal individuals with autism (4.S.G) to research on preventing secondary conditions associated with autism (such as obesity, injury, and co-occurring psychiatric and medical conditions; 4.S.H) to studies that assess the effectiveness of interventions and services in broader community settings (4.L.D). Many projects assessing educational interventions used in classrooms and school settings fall into this latter objective because the *Strategic Plan* does not currently include any specific objectives related to the education of children with autism.

Among the new objectives, research studies on interventions for nonverbal individuals and on interventions in community settings were both well underway (green light). The only objective in Question 4 that had not yet received funding support calls for a workshop to advance the understanding of clinical subtypes and treatment personalization (red light; 4.S.E).

From medications to alleviate common and co-occurring symptoms of the disorder to behavioral therapies to improve communication and learning, Question 4 includes varied approaches to treatments and interventions. Subsequently, there are several subcategories to describe the research in this question: Behavioral; Complementary, Dietary, and Alternative; Educational; Medical/Pharmacologic; Model systems/Therapeutic targets; Occupational, physical, and sensory-based; and Technology-based interventions and supports (Figure 8). The largest amount of funding supported early phases of intervention development. Specifically, \$24 million or 35% of projects in Question 4 represented efforts to develop Model systems and therapeutic targets, including animal models that exhibit behavioral characteristics similar to those observed in autism as well as cell lines used to test molecules as potential drug candidates. Research on Behavioral therapies (encompassing applied behavior analysis (ABA), the Lovaas method, cognitive behavioral therapy, social skills training, and joint attention training, among others) accounted for 29% of ASD research funding in Question 4, followed by research on Medical and pharmacologic interventions, which received 16% of the funding. Educational interventions, such as those used in a classroom setting, corresponded to 10% of research, and Technology-based interventions and supports, including augmentative and alternative communication (AAC) and robots to help children with ASD develop social skills, received 7% of the funding in Question 4. The subcategories with the smallest amounts of funding included Occupational, physical, and sensory-based therapies (2%) and Complementary, dietary, and alternative treatments (1%). These last two categories are more specialized therapeutic areas and include emerging approaches to treatments and interventions, so they were expected to be small, but distinct, areas of research.

Question 5: Services

The research in Question 5 (“Where Can I Turn for Services?”) encompasses services and supports for people with ASD, addressing issues including access to services, dissemination of evidence-based practices, and training of providers (pediatricians, teachers, social workers, etc.). Of the nine objectives in this question, five are partially fulfilled (yellow light), three have reached or exceeded the recommended budget amount (green light), and one objective lacked measureable progress (red light). Projects in Question 5 were assigned to a specific objective 79% of the time, with 21% of the funding not specific to question objectives (Figure 4).



The amount of research funding in Question 5 increased dramatically between 2009 and 2010, from \$8.6 million to \$64.8 million. This change was mostly attributed to more comprehensive reporting by the Health Resources and Services Administration (HRSA), including their Leadership Education in Neurodevelopmental Disabilities (LEND) program, which supports fellowships to pediatricians to enhance the behavioral, psychosocial, and developmental aspects of general pediatric care, as well as their Developmental Behavioral Pediatrics Training Programs at multiple

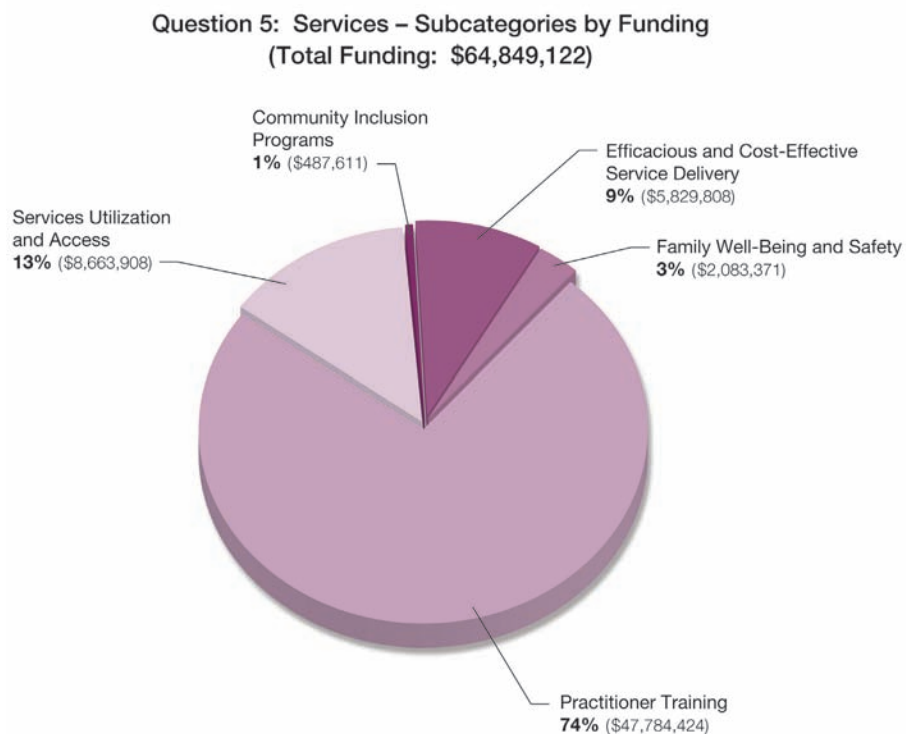


Figure 9. The Practitioner training subcategory in Question 5 dwarfed the other four categories, accounting for 74% of the funding for this question. Services utilization and access followed with 13% of the funding, and Efficacious and cost-effective service delivery accounted for 9%. Only 3% of funding was designated for projects related to Family well-being and safety, and even less (1%) for Community inclusion programs.

sites across the U.S. In addition, the Department of Education (ED) provided more comprehensive data for their autism-related portfolio, reporting significantly more projects in 2010, many of which involved training teachers in effective methods to engage students with ASD and other developmental disabilities.

The more comprehensive reporting by HRSA and ED were driving factors in improving the funding status for two objectives in 2010. One objective, which progressed from red to yellow, requires implementation and evaluation of coordination among State and local agencies to provide integrated and comprehensive community-based supports and services for individuals with ASD (5.S.C). The progress on this objective was led by HRSA's State ASD Demonstration projects. The objective that supports training to increase skill level in service providers progressed from yellow in 2009 to green in 2010, with the largest proportion of Question 5 funding (56%, \$36 million) in the *2010 Portfolio Analysis*.

Question 5 also had three new objectives to address in the 2010 analysis, including two involving health and safety issues for people with ASD (5.S.D and 5.L.D) and one examining dental health issues (5.L.E). As illustrated by the stoplight figure for this question, some progress is being made on all but one objective. The objective that lacked notable progress in 2010 calls for testing the efficacy and cost-effectiveness of evidence-based services and supports for people with ASD in community settings (5.L.B). Cost effectiveness research continues to be an area of needed growth in multiple disciplines of autism research.

The subcategories describing the research in Question 5 reflect some of the variety in service needs: Community inclusion programs, Efficacious and cost-effective service delivery, Family well-being and safety, Practitioner training, and Services utilization and access (Figure 9). Because of the broader reporting of autism-related services research projects by HRSA and ED in 2010, the largest subcategory was Practitioner training (74%). Services access and utilization (including potential barriers to access) accounted for 13% of the funding in Question 5, followed by Efficacious and cost-effective service delivery with 9%. This latter subcategory included several parent training projects (to deliver a behavioral therapy, for example), often using a remote, web-based format that would make distributing the training programs cost-effective and accessible across the country. Family well-being and safety projects received only 3% of the funding in Question 5, and Community inclusion programs received just 1%.

Question 6: Lifespan Issues

Although Question 6 (“What Does the Future Hold, Particularly for Adults?”) was the question in the *2010 Portfolio Analysis* with the smallest proportion of funding at only 2% (\$6.6 million), significant progress was made on this question when compared to 2009. In 2009, no progress had been made on five of the eight objectives, whereas in 2010, only one objective lacked any funding (red light). This objective (6.L.D) calls for research to test the results of comparative effectiveness research implemented in real-world settings that will improve health outcomes and quality of life for adults with ASD. Because comparative effectiveness research in the area of lifespan issues is quite limited, evaluating the implementation of this research may take a few years. On the other hand, the objective that seeks to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes (6.L.B) advanced from receiving part of the recommended funding in 2009 to receiving the full funding amount in 2010 (green in the stoplight figure). Ten percent of the funding for Question 6 supported research projects that were not related to the objectives in the *Strategic Plan* (Figure 4), and no new objectives were added to this question in 2011.

Because Question 6 only contained 34 projects, overlapping content made it difficult to generate distinct subcategories for the research. This question addresses issues across the ASD lifespan, including the transition into adulthood and adult services. This often incorporates training to help adolescents move from the education system to finding employment, and vocational training and job skills are key aspects of projects in Question 6. Social skills training to help people with ASD interact successfully with others in the workplace and in the community was also a common feature among projects. Many of the projects integrated training and services related to all of the above areas, which hampered efforts to separate them into distinct subcategories. Beyond those service areas, one project in Question 6 addressed adult diagnosis, and notably, a few studies involving treatments for adults were categorized within Question 4 (Treatments and Interventions) of the *Strategic Plan*. Although the current research on the lifespan of people with ASD is too narrow to divide into subcategories, this will likely change as the research field grows, and subcategories that encapsulate the scope of projects in this question may be defined in the future.



Question 7: Infrastructure and Surveillance

The research in Question 7 (“What Other Infrastructure and Surveillance Needs Must Be Met?”) covers the most diverse range of any other question in the *Strategic Plan* and has the largest number of objectives. Six objectives had the recommended amount of funding (green light), six were partially fulfilled (yellow light), and four were not yet funded (red light). This question received 12% (\$50.8 million) of ASD research funding in 2010, with three new objectives to address issues of research infrastructure. One of the new objectives seeks to enable clinical research sites to collect and coordinate comprehensive diagnostic, biological, medical, and treatment history data that would provide a platform for conducting comparative effectiveness research and clinical trials of novel autism treatments (7.N). The second new objective aims to create an information resource for autism researchers to facilitate data sharing and standardization of methods across projects, including common protocols and analytic techniques (7.O). The third new objective supports establishing facilities to develop and expand the availability and utility of animal models related to autism, along with high-throughput screening technology to evaluate the model systems (7.P).



Question 7: Infrastructure and Surveillance – Subcategories by Funding
(Total Funding: \$50,847,064)

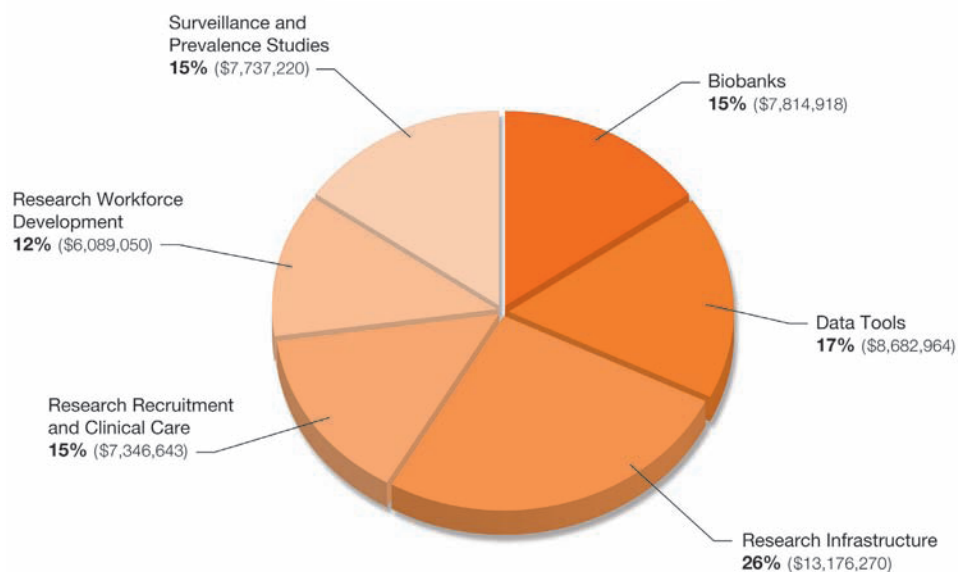


Figure 10. The subcategories in Question 7 cover a broad range of research areas, and funding was largely evenly distributed. Research infrastructure received 26% of the funding in Question 7, followed by Data tools with 17%. Biobanks and Surveillance and prevalence studies each received 15% of funding, Research recruitment and clinical care received 14% of funding, and Research workforce development received 12%.

At least some progress is being made on all of the new objectives, with two of them meeting the recommended budget amount (7.N and 7.P) and one partially meeting the goal (7.O). Four of the objectives in Question 7 did not receive any funding in 2009 or 2010. These objectives included establishing funding mechanisms for the rapid replication of research findings (7.F), developing databases to track the involvement of people with ASD in healthcare, education, and social services (7.A), “Promising Practices” papers describing innovative and successful services and supports (7.M), and developing a web-based tool that can provide current State-by-State ASD prevalence estimates (7.G). The two objectives that received the largest proportion of Question 7 funding in 2010 related to supporting biobanks with samples from individuals with autism to be used in research (7.D, 15%) and expanding the research workforce (7.K, 14%). In addition, 26% of the funding for projects in Question 7 was generally related to research involving infrastructure or surveillance, but not specific to an objective within that question (Figure 4).

The subcategories in Question 7 reflect the diverse array of projects covered by the objectives: Biobanks, Data tools, Research infrastructure, Research recruitment and clinical care, Research workforce development, and Surveillance and prevalence studies (Figure 10). Funding for the Research infrastructure subcategory was highest among the topic areas, with 26% of the funding share for Question 7. Data tools, such as the National Database for Autism Research (NDAR) and the Autism Genetics Resource Exchange (AGRE), comprised 17% of the research funding. Biobanks that collect DNA and tissue samples from autism patients received 15% of the research support, as did Surveillance and prevalence studies. The support in the latter subcategory was largely devoted to the Autism and Developmental Disabilities Monitoring (ADDM) Network, coordinated by the Centers for Disease Control and Prevention (CDC), which estimates autism prevalence in different areas of the United States. A few of the projects in this subcategory also examined autism prevalence internationally. Research recruitment and clinical care projects, which help increase participation in research studies and conduct medical evaluations for the participants, received 14% of funding in this question, and Research workforce development, which supports many conferences and training for autism researchers, received 12% of the funding for Question 7.

Impact of the American Recovery and Reinvestment Act on Autism Research

The American Recovery and Reinvestment Act (ARRA) was enacted by Congress in February 2009 with the objective of stimulating the economy, creating and preserving jobs, and investing in long-term growth. ARRA funds received by Federal agencies were awarded to grantees over a two-year period from 2009 to 2010. Thus, this *2010 Portfolio Analysis* includes data from 2010 ARRA grants as well as a comprehensive snapshot of all ARRA funds that supported autism research in 2009 and 2010. Among the Federal agencies that fund autism research projects, as described in this report, the National Institutes of Health (NIH), the National Science Foundation (NSF), and the Agency for Healthcare Research and Quality (AHRQ) reported use of ARRA funds to support autism research projects. The total funding and number of projects from each of these agencies can be found in Table 3 below. Please note that 2009 data for AHRQ and NSF were not captured in the *2009 Portfolio Analysis*; thus, only 2010 ARRA funding information was available for these funders.

In total, ARRA funds (\$123,916,638 million) comprised 17% of total ASD research funding across all participating Federal agencies and private organizations in 2009 and 2010 (Figure 11). This includes \$63,968,992 awarded by NIH in 2009 (27% of all ASD research in 2009) and \$59,947,646 in ARRA grants awarded by NIH, AHRQ, and NSF for 2010 (15% of all ASD research in 2010). Over the two year time period, Federal agencies distributed nearly \$572 million for autism research, and 22% of those funds came from ARRA (Figure 12).

2009 AND 2010 ARRA FUNDING ALLOCATED TO AUTISM RESEARCH			
Federal Agency	Number of projects	ARRA funding	Percent of total ARRA funding
National Institutes of Health	256	\$121,504,953	98%
National Science Foundation	8	\$1,361,172	1%
Agency for Healthcare Research and Quality	2	\$1,050,513	1%

Table 3. Three funders contributed to the total 2009 and 2010 ARRA funding of autism research (\$123,916,638). The NIH had the highest funding amount (98%; \$64 million in 2009 and \$58 million in 2010), and NSF and AHRQ each contributed about \$1 million (1%). Data for NSF and AHRQ were only available for 2010, and funding for NSF and AHRQ are estimated amounts.

Impact of ARRA on Total ASD Research Funding in 2009 & 2010
(Total Funding: \$722,962,650)

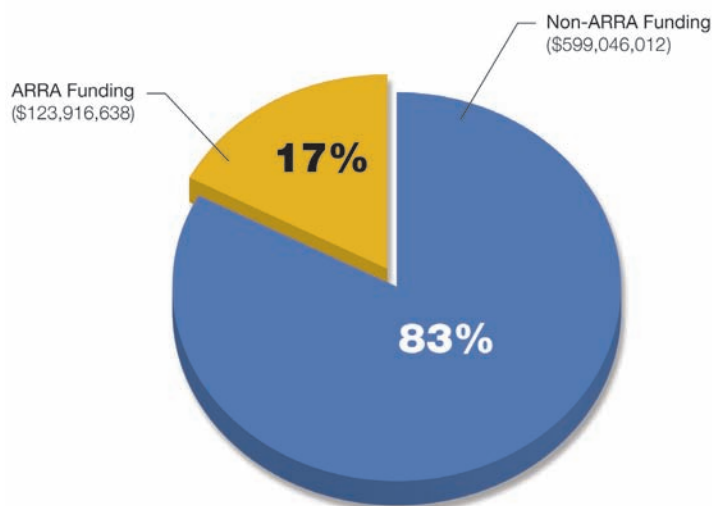


Figure 11. ARRA funding accounted for 17% (\$123,916,638) of autism research funding in 2009 and 2010. The funding total of nearly \$723 million represents support from Federal agencies and private organizations as reported in the 2009 and 2010 Portfolio Analyses.

Impact of ARRA on Federal ASD Research Funding in 2009 & 2010
(Total Funding: \$571,868,237)

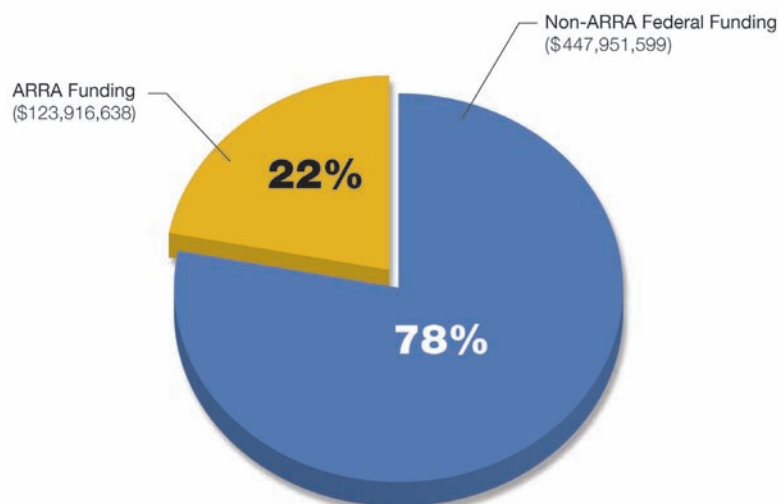


Figure 12. Seventy-eight percent of the \$571,868,237 distributed for ASD research by the Federal government in 2009 and 2010 was provided from non-ARRA funds, while the remaining 22% of Federal funding was from ARRA.

The NIH received \$8.2 billion total in ARRA funds to help stimulate the U.S. economy through support and advancement of biomedical research. The funds were used to initiate original research projects as well as to expand and enhance existing programs. Because autism was identified as a high priority area for research and the *IACC Strategic Plan* was in place at the time of ARRA's enactment, several NIH initiatives were developed to invest ARRA funds in this research. (A list of NIH ARRA initiatives that funded autism research can be found in Appendix C.) In 2009, nearly \$64 million in NIH ARRA funds were used to jumpstart the implementation of priorities described in the newly released *2009 IACC Strategic Plan for Autism Spectrum Disorder Research*, supporting 141 new autism research projects. In 2010, NIH used \$58 million in ARRA funds to sponsor 115 autism research projects. Many of the NIH-ARRA funded projects directly aligned with *IACC Strategic Plan* objectives, including research to identify biomarkers for early diagnosis, develop rapid screening instruments, identify subtypes of autism, explore underlying environmental and genetic risk factors, deliver behavioral therapy via telehealth technology, assist young adults with transition issues including employment, and understand autism in adults.

While the NIH awarded the largest portion of ARRA funding designated for autism research, ARRA projects supported by AHRQ and NSF also contributed significantly to the field. The *IACC 2011 Strategic Plan for ASD Research* identified comparative effectiveness research as a gap area, and AHRQ used ARRA funds to conduct comparative effectiveness research on treatments for ASD in adolescents and young adults. They also used ARRA funds to disseminate the best practices in autism treatments so that individuals, parents, and practitioners can make informed decisions. NSF used ARRA funds for eight projects, primarily studying the underlying biology of autism, particularly in the areas of speech, abnormal neural connectivity, and face recognition. They also supported projects to develop new technologies to recognize differences in the expression of affect (feeling and emotion) and to develop new measures of sensory motor function that could eventually be used for diagnosis of ASD in infants.

Impact of 2009-2010 ARRA Funding on IACC Strategic Plan Implementation

ARRA funding accounted for 17% of total ASD research funding in 2009 and 2010 (Figure 11), and Figure 13 conveys the distribution of all ARRA funding across the questions of the *IACC Strategic Plan*.

Research support received from ARRA focused largely on the identification of environmental and genetic risk factors for ASD (Question 3, 39%). Projects related to the underlying biology of ASD, including studies of genetically related disorders and co-occurring conditions, also received considerable support (Question 2, 23%). Diagnosis of ASD and treatments and interventions were also supported with ARRA funds (Question 1, 13% and Question 4, 12%, respectively). Research associated with services and lifespan issues received the least ARRA funding over the two year time period (5% and 2%, respectively), although ARRA investments in services research increased by one-third between 2009 and 2010 (from 4% to 6%), and lifespan research more than doubled (from 1% to almost 3%).

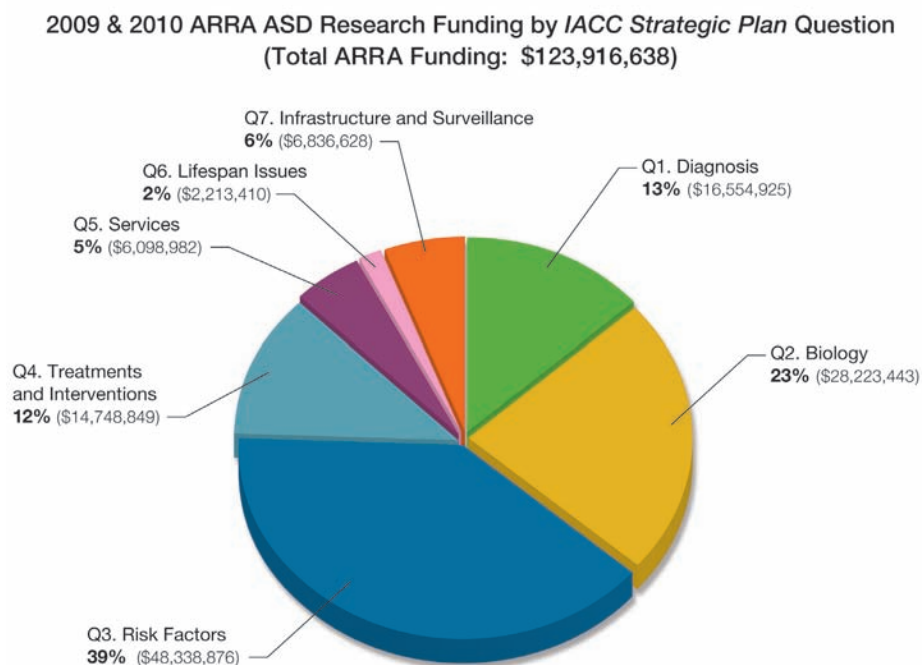


Figure 13. Topic areas are defined by each question in the IACC Strategic Plan. The largest proportion of ARRA ASD research funding (39%) was devoted to risk factors for ASD (Question 3); 23% of the research addressed the underlying biology of ASD (Question 2); 13% related to diagnosis (Question 1); 12% related to interventions and treatments (Question 4); 6% related to surveillance and infrastructure (Question 7); and 5% related to services (Question 5). Research on lifespan issues (Question 6) received just 2% of the ARRA ASD research funding. Projects that were not specific to Strategic Plan questions accounted for less than one percent of ARRA-funded research in autism (\$901,525; not shown on graph).

ARRA funds contributed significantly to several areas of the *IACC Strategic Plan* in 2009 and 2010. More than one-fourth of all funding for Question 6 (Lifespan Issues) and Question 3 (Risk Factors) came from ARRA (Figure 14). For Questions 1 and 2 (Diagnosis and Biology, respectively), ARRA supported more than 18% of the research. About a tenth of the research in the areas of treatments (Question 4) and infrastructure (Question 7) received ARRA funds, along with 8% of services research (Question 5).

While research funding for autism was already increasing prior to 2009, the influx of ARRA funds allowed additional funding to be applied to gap areas in research and stimulated even greater advances in the field. Although ARRA provided the opportunity to jumpstart new areas of research, budget uncertainty in the future has raised concern about the sustainability of progress in the years to come.

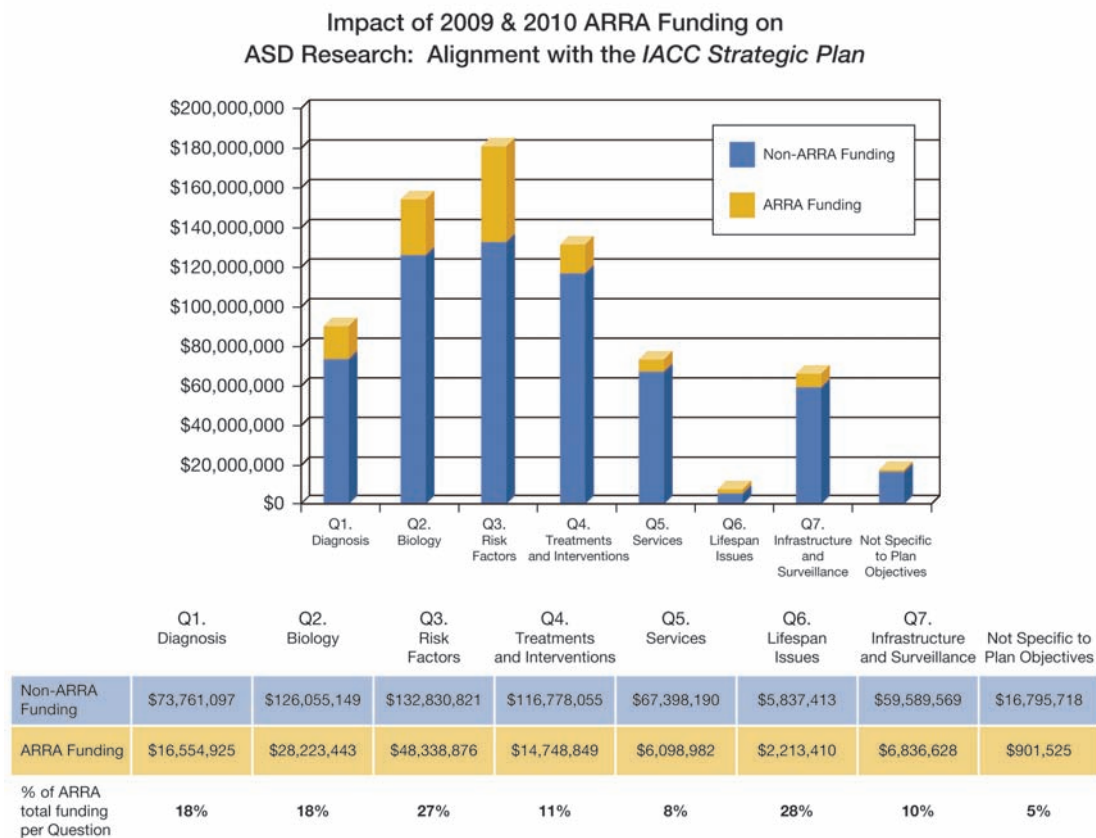


Figure 14. 2009 and 2010 ASD funding for each of the 2011 *IACC Strategic Plan* questions based on traditional funding sources or ARRA funding. Traditional funding is designated in blue, while ARRA funding is designated in yellow. ARRA funds comprised 27% of all funding for Questions 3 and 6, 18% of all funding for Questions 1 and 2, 11% of all funding for Question 4, 10% of all funding for Question 7, 8% of all funding for Question 5, and 5% of the funding for projects that were not specific to any of the *Strategic Plan* questions.

Conclusion

The *2010 ASD Research Funding Portfolio Analysis Report* is the third comprehensive annual review of ASD research funding across both the Federal and private sectors and provides a valuable snapshot of the current funding landscape. Total funding for ASD research in 2010 amounted to \$408,577,276 spread across 1,367 projects. Data were collected from 18 Federal and private funders, including 5 funders that were new to the *2010 Portfolio Analysis*. Because of the information gathered from these new funders, as well as increased reporting of activity in autism research from other funders, it is difficult to meaningfully compare the 2010 funding level to previous years. Total ASD research funding captured in the *2009 Portfolio Analysis* was a little more than \$314 million and in the 2008 report was \$222 million. The sustained and overall increase in autism investments each year indicates ongoing support and prioritization for this research, both in the Federal and private funding spheres.

The influx of ARRA funding in 2009 and 2010 enabled Federal funders to significantly augment their support of autism research. Overall, ARRA funds comprised 17% (\$123 million) of all ASD research funding in 2009 and 2010. Most of the funding was awarded by the National Institutes of Health (NIH), but the Agency for Healthcare Research and Quality (AHRQ) also reported 2 ARRA projects in 2010 (about \$1 million total) and the National Science Foundation (NSF) awarded about \$1.3 million in ARRA funds in 2010. (AHRQ and NSF were both new to the *2010 Portfolio Analysis*, so 2009 ARRA award amounts were not reflected in the *2009* or *2010 Portfolio Analysis Reports*.)

One aim of the *2010 Portfolio Analysis* was to evaluate progress made in addressing research priorities identified in the *2011 IACC Strategic Plan*. To that end, the analysis indicated that 83% of the 78 objectives in the *IACC Strategic Plan* were fully or partially fulfilled by research that was ongoing in the 2010 funding year, with only 13 objectives lacking any funding support. Of the sixteen new objectives added to the *2011 Plan*, fourteen of them were already underway in 2010.

The subcategory analysis of research projects within each question of the *Strategic Plan* was new to the *2010 Portfolio Analysis*. Dividing the research into more general subcategories complements the analysis of projects according to *Strategic Plan* objectives to present a comprehensive picture of the autism research funding landscape, including the areas that are not specific to a particular research objective. Over time, this subcategory analysis will allow tracking of growth and change in general research areas, including emergence of new fields that attract investment from research funders.

The IACC/OARC will continue to conduct annual portfolio analyses as a part of the Committee's charge to monitor research and to inform the process of updating the *IACC Strategic Plan for ASD Research*. Trends identified during the analysis can be used by the Committee and other Federal, private, and State funders to address gap areas, identify emerging trends and new research opportunities, and guide future research directions. By tracking new developments in autism research and inviting regular input from the community, the Committee will be well-equipped to continue charting the course toward a portfolio of research that meets the most pressing needs of families and individuals affected by ASD.

APPENDIX A

ASD Research Progress on 2011 IACC Strategic Plan Objectives

Data includes 2010 funding from Federal/private funders of ASD research and 2010 ARRA funding.

- Current project and funding status for each question or objective is indicated within the table by colored “dots” next to the objective. Any objective colored green has greater than or equal to the recommended funding; any objective colored yellow has some degree of funding, but less than the recommended amount; while any objective colored red has no funding.

NEW! Objectives labeled “New!” are either entirely new additions to the 2011 IACC Strategic Plan or significantly modified objectives from the 2010 IACC Strategic Plan. Objectives from the 2010 Strategic Plan that did not change or that have been slightly modified for clarification purposes in the 2011 Strategic Plan are unmarked.

QUESTION 1: WHEN SHOULD I BE CONCERNED?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
1.S.A 	Develop, with existing tools, at least one efficient diagnostic instrument (e.g., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. <i>IACC Recommended Budget: \$5,300,000 over 2 years.</i>	15 (9%)	\$4,963,192 (11%)	1%
1.S.B 	Validate and improve the sensitivity and specificity of new or existing screening and diagnostic tools, including comparative studies of general developmental screening versus autism-specific screening tools, in both high-risk and population-based samples, including those from resource-poor international settings and those that are diverse in terms of age, socioeconomic status, race, ethnicity, gender, characteristics of ASD, and general level of functioning by 2012. <i>IACC Recommended Budget: \$5,400,000 over 3 years.</i>	11 (7%)	\$2,443,557 (5%)	1%
1.S.C 	Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services, including identification of barriers to implementation of and access to screening, diagnosis, referral, and early intervention services among diverse populations, as defined by socioeconomic status, race, ethnicity, and gender of the child, by 2012. <i>IACC Recommended Budget: \$2,000,000 over 2 years.</i>	0	\$0	0%
1.S.D 	Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. <i>IACC Recommended Budget: \$6,000,000 over 5 years.</i>	0	\$0	0%
1.S.E  NEW!	Conduct at least one study to determine the positive predictive value and clinical utility (e.g., prediction of co-occurring conditions, family planning) of chromosomal microarray genetic testing for detecting genetic diagnoses for ASD in a clinical setting by 2012. <i>IACC Recommended Budget: \$9,600,000 over 5 years.</i>	3 (2%)	\$2,180,042 (5%)	1%
1.S.F  NEW!	Convene a workshop to examine the ethical, legal, and social implications of ASD research by 2011. The workshop should define possible approaches for conducting future studies of ethical, legal, and social implications of ASD research, taking into consideration how these types of issues have been approached in related medical conditions <i>IACC Recommended Budget: \$35,000 over 1 year.</i>	0	\$0	0%
1.L.A 	Identify behavioral and biological markers that separately, or in combination, accurately identify, before age 2, one or more subtypes of children at risk for developing ASD, and evaluate whether these risk markers or profiles can improve early identification through heightened developmental monitoring and screening by 2014. <i>IACC Recommended Budget: \$33,300,000 over 5 years.</i>	45 (27%)	\$13,270,045 (29%)	3%

QUESTION 1: WHEN SHOULD I BE CONCERNED?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
1.L.B ●	Develop at least five measures of behavioral and/or biological heterogeneity in children or adults with ASD, beyond variation in intellectual disability, that clearly relate to etiology and risk, treatment response and/or outcome by 2015. <i>IACC Recommended Budget: \$71,100,000 over 5 years.</i>	52 (31%)	\$15,228,060 (33%)	4%
1.L.C ●	Identify and develop measures to assess at least three “continuous dimensions” (i.e., social reciprocity, communication disorders, and repetitive/restrictive behaviors) of ASD symptoms and severity that can be used by practitioners and/or families to assess response to intervention for people with ASD across the lifespan by 2016. <i>IACC Recommended Budget: \$18,500,000 over 5 years.</i>	22 (13%)	\$3,893,622 (9%)	1%
1.Other	Not specific to any objective	18 (11%)	\$3,643,562 (8%)	1%
Total Funding for Question 1		166 (100%)	\$45,622,080 (100%)	11%

The percentages noted in parentheses in the “Projects” and “Funding” columns indicate the fraction of all projects or funding within that specific question, whereas the percentage in the “Percent of Total ASD Funding” column indicates the percent of the entire ASD research funding portfolio for 2010. Due to rounding, the percentages within a question may not equal exactly 100%.

QUESTION 2: HOW CAN I UNDERSTAND WHAT IS HAPPENING?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
2.S.A 	Support at least four research projects to identify mechanisms of fever, metabolic and/or immune system interactions with the central nervous system that may influence ASD during prenatal-postnatal life by 2010. <i>IACC Recommended Budget: \$9,800,000 over 4 years. (Fever studies to be started by 2012.)</i>	37 (9%)	\$4,972,407 (5%)	1%
2.S.B 	Launch three studies that specifically focus on the neurodevelopment of females with ASD, spanning basic to clinical research on sex differences by 2011. <i>IACC Recommended Budget: \$8,900,000 over 5 years.</i>	5 (1%)	\$1,096,678 (1%)	<1%
2.S.C 	Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research by 2011. <i>IACC Recommended Budget: \$1,400,000 over 2 years.</i>	1 (<1%)	\$17,000 (<1%)	<1%
2.S.D 	Launch three studies that target improved understanding of the underlying biological pathways of genetic conditions related to autism (e.g. Fragile X, Rett syndrome, tuberous sclerosis complex) and how these conditions inform risk assessment and individualized intervention by 2012. <i>IACC Recommended Budget: \$9,000,000 over 5 years.</i>	57 (14%)	\$13,162,905 (14%)	3%
2.S.E 	Launch three studies that target the underlying biological mechanisms of co-occurring conditions with autism, including seizures/epilepsy, sleep disorders, wandering/elopement behavior, and familial autoimmune disorders, by 2012. <i>IACC Recommended Budget: \$9,000,000 over 5 years.</i>	14 (3%)	\$4,611,058 (5%)	1%
2.S.F 	Launch two studies that focus on prospective characterization of children with reported regression to investigate potential risk factors by 2012. <i>IACC Recommended Budget: \$4,500,000 over 5 years.</i>	2 (<1%)	\$401,595 (<1%)	<1%
2.S.G 	Support five studies that associate specific genotypes with functional or structural phenotypes, including behavioral and medical phenotypes (e.g., nonverbal individuals with ASD and those with cognitive impairments) by 2015. <i>IACC Recommended Budget: \$22,600,000 over 5 years.</i>	39 (10%)	\$9,149,672 (10%)	2%
2.L.A 	Complete a large-scale, multi-disciplinary, collaborative project that longitudinally and comprehensively examines how the biological, clinical, and developmental profiles of individuals, with a special emphasis on females, youths, and adults with ASD, change over time as compared to typically developing people by 2020. <i>IACC Recommended Budget: \$126,200,000 over 12 years.</i>	6 (1%)	\$2,283,875 (3%)	1%

QUESTION 2: HOW CAN I UNDERSTAND WHAT IS HAPPENING?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
2.L.B 	Launch at least three studies which evaluate the applicability of ASD phenotype and/or biological signature findings for performing diagnosis, risk assessment, or clinical intervention by 2015. <i>IACC Recommended Budget: \$7,200,000 over 5 years.</i>	2 (<1%)	\$450,271 (<1%)	<1%
2.Other	Not specific to any objective	246 (60%)	\$55,114,888 (60%)	13%
Total Funding for Question 2		409 (100%)	\$91,260,349 (100%)	22%

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QUESTION 3: WHAT CAUSED THIS TO HAPPEN AND CAN IT BE PREVENTED?

2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
3.S.A 	Coordinate and implement the inclusion of approximately 20,000 subjects for genome-wide association studies, as well as a sample of 1,200 for sequencing studies to examine more than 50 candidate genes by 2011. Studies should investigate factors contributing to phenotypic variation across individuals that share an identified genetic variant and stratify subjects according to behavioral, cognitive, and clinical features. <i>IACC Recommended Budget: \$43,700,000 over 4 years.</i>	14 (9%)	\$16,688,932 (21%)	4%
3.S.B 	Within the highest priority categories of exposures for ASD, identify and standardize at least three measures for identifying markers of environmental exposure in biospecimens by 2011. <i>IACC Recommended Budget: \$3,500,000 over 3 years.</i>	0	\$0	0%
3.S.C 	Initiate efforts to expand existing large case-control and other studies to enhance capabilities for targeted gene – environment research by 2011. <i>IACC Recommended Budget: \$27,800,000 over 5 years.</i>	8 (5%)	\$4,824,779 (6%)	1%
3.S.D 	Enhance existing case-control studies to enroll racially and ethnically diverse populations affected by ASD by 2011. <i>IACC Recommended Budget: \$3,300,000 over 5 years.</i>	0	\$0	0%
3.S.E 	Support at least two studies to determine if there are subpopulations that are more susceptible to environmental exposures (e.g., immune challenges related to infections, vaccinations, or underlying autoimmune problems) by 2012. <i>IACC Recommended Budget: \$8,000,000 over 2 years.</i>	10 (6%)	\$1,162,679 (1%)	<1%
3.S.F 	Initiate studies on at least 10 environmental factors identified in the recommendations from the 2007 IOM report “Autism and the Environment: Challenges and Opportunities for Research” as potential causes of ASD by 2012. <i>IACC Recommended Budget: \$56,000,000 over 2 years.</i>	5 (3%)	\$166,362 (<1%)	<1%
3.S.G  NEW!	Convene a workshop that explores the usefulness of bioinformatic approaches to identify environmental risks for ASD by 2011. <i>IACC Recommended Budget: \$35,000 over 1 year.</i>	0	\$0	0%
3.S.H  NEW!	Support at least three studies of special populations or use existing databases to inform our understanding of environmental risk factors for ASD in pregnancy and the early postnatal period by 2012. Such studies could include: • Comparisons of populations differing in geography, gender, ethnic background, exposure history (e.g., prematurity, maternal infection, nutritional deficiencies, toxins), and migration patterns; and • Comparisons of phenotype (e.g., cytokine profiles), in children with and without a history of autistic regression, adverse events following immunization (such as fever and seizures), and mitochondrial impairment. These studies may also include comparisons of phenotype between children with regressive ASD and their siblings. • Emphasis on environmental factors that influence prenatal and early postnatal development is particularly of high priority. Epidemiological studies should pay special attention to include racially and ethnically diverse populations. <i>IACC Recommended Budget: \$12,000,000 over 5 years.</i>	13 (8%)	\$1,527,866 (2%)	<1%

QUESTION 3: WHAT CAUSED THIS TO HAPPEN AND CAN IT BE PREVENTED?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
3.S.I  NEW!	Support at least two studies that examine potential differences in the microbiome of individuals with ASD versus comparison groups by 2012. <i>IACC Recommended Budget: \$1,000,000 over 2 years.</i>	3 (2%)	\$53,960 (<1%)	<1%
3.S.J  NEW!	Support at least three studies that focus on the role of epigenetics in the etiology of ASD, including studies that include assays to measure DNA methylations and histone modifications and those exploring how exposures may act on maternal or paternal genomes via epigenetic mechanisms to alter gene expression, by 2012. <i>IACC Recommended Budget: \$20,000,000 over 5 years.</i>	15 (9%)	\$5,072,389 (6%)	1%
3.S.K  NEW!	Support two studies and a workshop that facilitate the development of vertebrate and invertebrate model systems for the exploration of environmental risks and their interaction with gender and genetic susceptibilities for ASD by 2012. <i>IACC Recommended Budget: \$1,535,000 over 3 years.</i>	5 (3%)	\$733,922 (1%)	<1%
3.L.A 	Conduct a multi-site study of the subsequent pregnancies of 1,000 women with a child with ASD to assess the impact of environmental factors in a period most relevant to the progression of ASD by 2014. <i>IACC Recommended Budget: \$11,100,000 over 5 years.</i>	2 (1%)	\$2,971,093 (4%)	1%
3.L.B 	Identify genetic risk factors in at least 50% of people with ASD by 2014. <i>IACC Recommended Budget: \$33,900,000 over 6 years.</i>	60 (37%)	\$34,432,884 (42%)	8%
3.L.C 	Determine the effect of at least five environmental factors on the risk for subtypes of ASD in the pre- and early postnatal period of development by 2015. <i>IACC Recommended Budget: \$25,100,000 over 7 years.</i>	10 (6%)	\$820,320 (1%)	<1%
3.L.D 	Support ancillary studies within one or more large-scale, population-based surveillance and epidemiological studies, including U.S. populations, to collect data on environmental factors during preconception, and during prenatal and early postnatal development, as well as genetic data, that could be pooled (as needed), to analyze targets for potential gene/environment interactions by 2015. <i>IACC Recommended Budget: \$44,400,000 over 5 years.</i>	10 (6%)	\$11,464,011 (14%)	3%
3.Other	Not specific to any objective	7 (4%)	\$1,312,450 (2%)	<1%
Total Funding for Question 3		162 (100%)	\$81,231,647 (100%)	20%

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QUESTION 4: WHICH TREATMENTS AND INTERVENTIONS WILL HELP?

2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
4.S.A 	Support at least three randomized controlled trials that address co-occurring medical conditions associated with ASD by 2010. <i>IACC Recommended Budget: \$13,400,000 over 3 years.</i>	4 (1%)	\$3,787,700 (6%)	1%
4.S.B 	Standardize and validate at least 20 model systems (e.g., cellular and/or animal) that replicate features of ASD and will allow identification of specific molecular targets or neural circuits amenable to existing or new interventions by 2012. <i>IACC Recommended Budget: \$75,000,000 over 5 years.</i>	92 (33%)	\$23,229,501 (34%)	6%
4.S.C 	Test safety and efficacy of at least five widely used interventions (e.g., nutrition, medications, assisted technologies, sensory integration, medical procedures) that have not been rigorously studied for use in ASD by 2012. <i>IACC Recommended Budget: \$27,800,000 over 5 years.</i>	18 (6%)	\$1,509,745 (2%)	<1%
4.S.D 	Complete two multi-site randomized controlled trials of comprehensive early intervention that address core symptoms, family functioning and community involvement by 2013. <i>IACC Recommended Budget: \$16,700,000 over 5 years.</i>	18 (6%)	\$10,306,148 (15%)	3%
4.S.E 	Convene a workshop to advance the understanding of clinical subtypes and treatment personalization (i.e., what are the core symptoms to target for treatment studies) by 2011. <i>IACC Recommended Budget: \$50,000.</i>	0	\$0	0%
4.S.F 	Launch five randomized controlled trials of interventions including biological signatures and other measures to predict response, and monitor quality of life and functional outcomes, in each of the following groups: - Five trials in infants and toddlers by 2013. <i>IACC Recommended Budget: \$30,000,000 over 5 years.</i> - Three randomized controlled trials of interventions for school-aged children and/or adolescents by 2013. <i>IACC Recommended Budget: \$18,000,000 over 5 years.</i> - Three trials for adults by 2014. <i>IACC Recommended Budget: \$18,000,000 over 5 years.</i>	30 (11%)	\$7,575,212 (11%)	2%
4.S.G  NEW!	Support at least five studies on interventions for nonverbal individuals with ASD by 2012. Such studies may include: - Projects examining service-provision models that enhance access to augmentative and alternative communication (AAC) supports in both classroom and adult service-provision settings, such as residential service-provision and the impact of such access on quality of life, communication, and behavior; - Studies of novel treatment approaches that facilitate communication skills in individuals who are nonverbal, including the components of effective AAC approaches for specific subpopulations of people with ASD; and - Studies assessing access and use of AAC for children and adults with ASD who have limited or partially limited speech and the impact on functional outcomes and quality of life. <i>IACC Recommended Budget: \$3,000,000 over 2 years.</i>	11 (4%)	\$1,907,721 (3%)	<1%

QUESTION 4: WHICH TREATMENTS AND INTERVENTIONS WILL HELP?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
4.S.H ● NEW!	Support at least two studies that focus on research on health promotion and prevention of secondary conditions in people with ASD by 2012. Secondary conditions of interest include weight issues and obesity, injury, and co-occurring psychiatric and medical conditions. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>	2 (1%)	\$225,877 (<1%)	<1%
4.L.A ●	Complete at least three randomized controlled trials on medications targeting core symptoms in people with ASD of all ages by 2014. <i>IACC Recommended Budget: \$22,200,000 over 5 years.</i>	11 (4%)	\$1,924,932 (3%)	<1%
4.L.B ●	Develop interventions for siblings of people with ASD with the goal of reducing risk recurrence by at least 30% by 2014. <i>IACC Recommended Budget: \$6,700,000 over 5 years.</i>	3 (1%)	\$307,349 (<1%)	<1%
4.L.C ●	Conduct at least one study to evaluate the safety and effectiveness of medications commonly used in the treatment of co-occurring conditions or specific behavioral issues in people with ASD by 2015. <i>IACC Recommended Budget: \$10,000,000 over 5 years.</i>	7 (3%)	\$2,302,240 (3%)	1%
4.L.D ● NEW!	Support at least five community-based studies that assess the effectiveness of interventions and services in broader community settings by 2015. Such studies may include comparative effectiveness research studies that assess the relative effectiveness of: • Different and/or combined medical, pharmacological, nutritional, behavioral, service-provision, and parent- or caregiver-implemented treatments; • Scalable early intervention programs for implementation in underserved, low-resource, and low-literacy populations; and • Studies of widely used community intervention models for which extensive published data are not available. Outcome measures should include assessment of potential harm as a result of autism treatments, as well as positive outcomes. <i>IACC Recommended Budget: \$37,500,000 over 5 years.</i>	32 (12%)	\$8,756,832 (13%)	2%
4.Other	Not specific to any objective	49 (18%)	\$6,290,633 (9%)	2%
Total Funding for Question 4		277 (100%)	\$68,123,890 (100%)	17%

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QUESTION 5: WHERE CAN I TURN FOR SERVICES?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
5.S.A 	Support two studies that assess how variations and access to services affect family functioning in diverse populations, including underserved populations, by 2012. <i>IACC Recommended Budget: \$1,000,000 over 3 years.</i>	9 (4%)	\$2,061,834 (3%)	1%
5.S.B 	Conduct one study to examine how self-directed community-based services and supports impact children, youth, and adults with ASD across the spectrum by 2014. <i>IACC Recommended Budget: \$6,000,000 over 3 years.</i>	6 (3%)	\$291,635 (<1%)	<1%
5.S.C 	Implement and evaluate five models of policy and practice-level coordination among State and local agencies to provide integrated and comprehensive community-based supports and services that enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with ASD across the spectrum and their families, (which may include access to augmentative and alternative communication [AAC] technology), with at least one project aimed at the needs of transitioning youth and at least one study to evaluate a model of policy and practice-level coordination among State and local mental health agencies serving people with ASD, by 2015. <i>IACC Recommended Budget: \$25,000,000 over 5 years.</i>	15 (7%)	\$4,225,315 (7%)	1%
5.S.D  NEW!	Support two studies to examine health, safety, and mortality issues for people with ASD by 2012. <i>IACC Recommended Budget: \$4,500,000 over 3 years.</i>	3 (1%)	\$159,135 (<1%)	<1%
5.L.A 	Test four methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings by 2013. <i>IACC Recommended Budget: \$7,000,000 over 5 years.</i>	22 (10%)	\$7,747,912 (12%)	2%
5.L.B 	Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for people with ASD across the spectrum and of all ages living in community settings by 2015. <i>IACC Recommended Budget: \$16,700,000 over 5 years.</i>	0	\$0	0%
5.L.C 	Evaluate new and existing pre-service and in-service training to increase skill levels in service providers, including direct support workers, parents and legal guardians, education staff, and public service workers to benefit the spectrum of people with ASD and promote interdisciplinary practice by 2015. <i>IACC Recommended Budget: \$8,000,000 over 5 years.</i>	83 (39%)	\$36,433,257 (56%)	9%

QUESTION 5: WHERE CAN I TURN FOR SERVICES?				
2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
5.L.D ● NEW!	Evaluate at least two strategies or programs to increase the health and safety of people with ASD that simultaneously consider principles of self-determination and personal autonomy by 2015. <i>IACC Recommended Budget: \$2,000,000 over 2 years.</i>	5 (2%)	\$296,840 (<1%)	<1%
5.L.E ● NEW!	Support three studies of dental health issues for people with ASD by 2015. This should include: - One study on the cost-benefit of providing comprehensive dental services, including routine, non-emergency medical and surgical dental services, denture coverage, and sedation dentistry to adults with ASD as compared to emergency and/or no treatment. <i>IACC Recommended Budget: \$900,000 over 3 years.</i> - One study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to people with ASD. <i>IACC Recommended Budget: \$900,000 over 3 years.</i> - One study evaluating pre-service and in-service training program to increase skill levels in oral health professionals to benefit people with ASD and promote interdisciplinary practice. <i>IACC Recommended Budget: \$900,000 over 3 years.</i>	2 (1%)	\$196,457 (<1%)	<1%
5.Other	Not specific to any objective	66 (31%)	\$13,436,737 (21%)	3%
Total Funding for Question 5		211 (100%)	\$64,849,122 (100%)	16%

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QUESTION 6: WHAT DOES THE FUTURE HOLD, PARTICULARLY FOR ADULTS?

2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
6.S.A 	Launch at least two studies to assess and characterize variation in the quality of life for adults on the ASD spectrum as it relates to characteristics of the service delivery system (e.g., safety, integrated employment, post-secondary educational opportunities, community inclusion, self-determination, relationships, and access to health services and community-based services) and determine best practices by 2012. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>	2 (6%)	\$283,837 (4%)	<1%
6.S.B 	Evaluate at least one model, at the state and local level, in which existing programs to assist people with disabilities (e.g., Social Security Administration, Rehabilitation Services Administration) meet the needs of transitioning youth and adults with ASD by 2013. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>	2 (6%)	\$700,000 (11%)	<1%
6.S.C 	Develop one method to identify adults across the ASD spectrum who may not be diagnosed, or are misdiagnosed, to support service linkage, better understand prevalence, track outcomes, with consideration of ethical issues (insurance, employment, stigma) by 2015. <i>IACC Recommended Budget: \$8,400,000 over 5 years.</i>	1 (3%)	\$28,000 (<1%)	<1%
6.S.D 	Conduct at least one study to measure and improve the quality of life-long supports being delivered in community settings to adults across the spectrum with ASD through provision of specialized training for direct care staff, parents, and legal guardians, including assessment and development of ASD-specific training, if necessary, by 2015. <i>IACC Recommended Budget: \$7,500,000 over 5 years.</i>	3 (9%)	\$619,163 (9%)	<1%
6.L.A 	Develop at least two individualized community-based interventions that improve quality of life or health outcomes for the spectrum of adults with ASD by 2015. <i>IACC Recommended Budget: \$12,900,000 over 5 years.</i>	18 (53%)	\$2,285,071 (34%)	1%
6.L.B 	Conduct one study that builds on carefully characterized cohorts of children and youth with ASD to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes by 2015. <i>IACC Recommended Budget: \$5,000,000 over 5 years.</i>	3 (9%)	\$1,280,790 (19%)	<1%

QUESTION 6: WHAT DOES THE FUTURE HOLD, PARTICULARLY FOR ADULTS?

2011 IACC Strategic Plan Objectives		Projects	Funding	Percent of Total ASD Funding
6.L.C 	Conduct comparative effectiveness research that includes a cost-effectiveness component to examine community-based interventions, services, and supports to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2018. Topics should include: • Community housing for people with ASD; • Successful life transitions for people with ASD, including from post-secondary education to adult services, employment, sibling relationships, and day programs; and • Meeting the service and support needs of older adults with ASD. <i>IACC Recommended Budget: \$6,000,000 over 5 years.</i>	2 (6%)	\$774,644 (12%)	<1%
6.L.D 	Conduct implementation research to test the results from comparative effectiveness research in real-world settings including a cost-effectiveness component to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2023. <i>IACC Recommended Budget: \$4,000,000 over 5 years.</i>	0	\$0	0%
6.Other	Not specific to any objective	3 (9%)	\$671,619 (10%)	<1%
Total Funding for Question 6		34 (100%)	\$6,643,124 (100%)	2%

The percentages noted in parentheses in the "Projects" and "Funding" columns indicate the fraction of all projects or funding within that specific question, whereas the percentage in the "Percent of Total ASD Funding" column indicates the percent of the entire ASD research funding portfolio for 2010. Due to rounding, the percentages within a question may not equal exactly 100%.

QUESTION 7: WHAT OTHER INFRASTRUCTURE AND SURVEILLANCE NEEDS MUST BE MET?				
2011 IACC Strategic Plan Objectives		Projects	Amount	Percent of Total ASD Funding
7.A 	Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in healthcare, education and social services by 2009. <i>IACC Recommended Budget: \$520,000 over 1 year.</i>	0	\$0	0%
7.B 	Conduct an annual "State of the States" assessment of existing State programs and supports for people and families living with ASD by 2011. <i>IACC Recommended Budget: \$300,000 each year.</i>	1 (1%)	\$197,128 (<1%)	<1%
7.C 	Develop and have available to the research community means by which to merge or link databases that allow for tracking the involvement of people in ASD research by 2010. <i>IACC Recommended Budget: \$1,300,000 over 2 years.</i>	5 (5%)	\$2,785,368 (5%)	1%
7.D 	Establish and maintain an international network of biobanks for the collection of brain, fibroblasts for pluripotent stem cells, and other tissue or biological material, by acquisition sites that use standardized protocols for phenotyping, collection, and regulated distribution of limited samples by 2011. • This includes support for post-processing of tissue, such as genotyping, RNA expression profiling, and MRI. • Protocols should be put into place to expand the capacities of ongoing large-scale children's studies to collect and store additional biomaterials, including newborn bloodspots, promoting detection of biological signatures. • Support should also be provided to develop an international web-based digital brain atlas that would provide high-resolution 3-D images and quantitative anatomical data from tissue of patients with ASD and disease controls across the lifespan, which could serve as an online resource for quantitative morphological studies, by 2014. <i>IACC Recommended Budget: \$82,700,000 over 5 years.</i>	6 (6%)	\$7,814,918 (15%)	2%
7.E 	Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their finding to the community, including people with ASD, their families, and health practitioners by 2011. <i>IACC Recommended Budget: \$400,000 over 2 years.</i>	1 (1%)	\$390,134 (1%)	<1%
7.F 	Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011. <i>(No recommended budget assigned by the IACC.)</i>	0	\$0	0%

QUESTION 7: WHAT OTHER INFRASTRUCTURE AND SURVEILLANCE NEEDS MUST BE MET?

2011 IACC Strategic Plan Objectives		Projects	Amount	Percent of Total ASD Funding
7.G 	Develop a web-based tool which provides population estimates of ASD prevalence for states based on the most recent prevalence range and average identified by the ADDM Network by 2012. <i>IACC Recommended Budget: \$200,000 over 2 years.</i>	0	\$0	0%
7.H 	Create mechanisms to specifically support the contribution of data from 90 percent of newly initiated projects to the National Database for Autism Research (NDAR) and link NDAR with other existing data resources by 2012. <i>IACC Recommended Budget: \$6,800,000 over 2 years.</i>	3 (3%)	\$2,453,253 (5%)	1%
7.I 	Supplement existing ADDM Network sites to use population-based surveillance data to conduct at least 5 hypothesis-driven analyses evaluating factors that may contribute to changes in ASD prevalence by 2012. <i>IACC Recommended Budget: \$660,000 over 2 years.</i>	13 (12%)	\$6,137,128 (12%)	2%
7.J 	Develop the personnel and technical infrastructure to assist states, territories, and other countries who request assistance describing and investigating potential changes in the prevalence of ASD and other developmental disabilities by 2013. <i>IACC Recommended Budget: \$1,650,000 over 3 years.</i>	4 (4%)	\$170,490 (<1%)	<1%
7.K 	Encourage programs and funding mechanisms that expand the research workforce, enhance interdisciplinary research training, and recruit early career scientists into the ASD field by 2013. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>	34 (31%)	\$7,358,427 (14%)	2%
7.L 	Expand the number of ADDM sites in order to conduct ASD surveillance in children and adults; conduct complementary direct screening to inform completeness of ongoing surveillance; and expand efforts to include autism subtypes by 2015. <i>IACC Recommended Budget: \$16,200,000 over 5 years.</i>	8 (7%)	\$1,429,602 (3%)	<1%
7.M 	Support 10 "Promising Practices" papers that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with ASD, which can be replicated in other communities by 2015. <i>IACC Recommended Budget: \$75,000 over 5 years.</i>	0	\$0	0%

The percentages noted in parentheses in the "Projects" and "Funding" columns indicate the fraction of all projects or funding within that specific question, whereas the percentage in the "Percent of Total ASD Funding" column indicates the percent of the entire ASD research funding portfolio for 2010. Due to rounding, the percentages within a question may not equal exactly 100%.

QUESTION 7: WHAT OTHER INFRASTRUCTURE AND SURVEILLANCE NEEDS MUST BE MET?

2011 IACC Strategic Plan Objectives		Projects	Amount	Percent of Total ASD Funding
7.N  NEW!	Enhance networks of clinical research sites offering clinical care in real-world settings that can collect and coordinate standardized and comprehensive diagnostic, biological (e.g., DNA, plasma, fibroblasts, urine), medical, and treatment history data that would provide a platform for conducting comparative effectiveness research and clinical trials of novel autism treatments by 2012. <i>IACC Recommended Budget: \$1,850,000 over 1 year.</i>	3 (3%)	\$6,662,790 (13%)	2%
7.O  NEW!	Create an information resource for ASD researchers (e.g., PhenX Project) to share information to facilitate data sharing and standardization of methods across projects by 2013. - This includes common protocols, instruments, designs, and other procedural documents and should include updates on new technology and links to information on how to acquire and utilize technology in development. - This can serve as a bidirectional information reference, with autism research driving the development of new resources and technologies, including new model systems, screening tools, and analytic techniques. <i>IACC Recommended Budget: \$2,000,000 over 2 years.</i>	3 (3%)	\$605,338 (1%)	<1%
7.P  NEW!	Provide resources to centers or facilities that develop promising vertebrate and invertebrate model systems, and make these models more easily available or expand the utility of current model systems, and support new approaches to develop high-throughput screening technologies to evaluate the validity of model systems by 2013. <i>IACC Recommended Budget: \$1,100,000 over 2 years.</i>	1 (1%)	\$1,588,780 (3%)	<1%
7.Other	Not specific to any objective	26 (24%)	\$13,253,709 (26%)	3%
Total Funding for Question 7		108 (100%)	\$50,847,065 (100%)	12%

2011 IACC Strategic Plan Objectives	Projects	Amount	Percent of Total ASD Funding
Total ASD Funding for 2010	1,367	\$408,577,276	100%

APPENDIX B

Subcategory Definitions

Question 1: Diagnosis

Diagnostic and screening tools: This subcategory includes projects that are developing new autism diagnostic and screening tests, as well as those establishing the usefulness of new or revised assessments for autism symptoms. It also encompasses projects aimed at adapting clinical assessments into other languages for use in multi-lingual community settings and non-U.S. countries.

Early signs and biomarkers: Projects which use a variety of methods to search for signs of autism in very young children (generally under age 3) that could be used for diagnosis, such as eye-tracking, physiological measures, and autism-specific behavioral patterns are included in this subcategory. More examples include projects investigating metabolic measures, such as the levels of specific chemicals, hormones, or proteins in the blood that could be used as biomarkers of the disorder.

Intermediate phenotypes/Subgroups: Included in this subcategory are projects aimed at identifying distinct subgroups of people with autism, or those that share common morphological, physiological, or behavioral features. Projects in this subcategory use a variety of methods to identify and distinguish these groups.

Symptomology: These projects seek to define the broad range and severity of autism symptoms, including both biological and behavioral characteristics. Among these studies are some that examine how children and adults with autism vary in their development of social communication and language. Other projects seek to understand the emergence of problem behaviors and how neurocognitive impairments can contribute to symptom development and phenotypic variability in those with an autism diagnosis.

Question 2: Biology

Cognitive studies: These are studies of psychological and mental processes, including memory, producing and understanding language, solving problems, and making decisions. Projects in this subcategory consist of those that investigate theory of mind, social cognition and empathy, understanding facial expressions of emotion (and how and why this is impaired in ASD), and recall and memory.

Computational science: Computational methods and modeling allow for the synthesis and study of large and complex sets of data. Some projects in this subcategory collect extensive experimental biological and behavioral data and use powerful computing techniques to reveal new insights. Other aspects of computer science are also included, such as developing statistical modeling techniques to better understand the biology of autism.

Co-occurring conditions: Research on conditions that often co-occur with ASD is included here, such as seizures/epilepsy, sleep disorders, gastrointestinal dysfunction, wandering/elopement behavior, attention deficit hyperactivity disorder (ADHD), and familial autoimmune disorders.

Developmental trajectory: Projects in this subcategory often include longitudinal studies following various aspects of biological and behavioral development in the same individuals over time. Examples include brain growth, face processing, change in neural connectivity over time, and development of communication skills and language processing. These studies often compare children with ASD to typically developing children or to their unaffected siblings.

Immune/Metabolic pathways: These projects focus on understanding the biological mechanisms of metabolism and the immune system that may be altered in autism, typically in cells and animal models. This largely includes studies on inflammation and inflammatory molecules (i.e., cytokines), as well as on the role of mitochondria, energy metabolism, and oxidative stress. Also included in this group are projects seeking to identify specific immune and metabolic triggers in early prenatal and post-natal life, such as maternal infection, maternal auto-antibodies, and toxic exposures.

Molecular pathways: This subcategory includes studies on specific molecules and proteins (other than the immune and metabolic systems) that may be involved in the development of ASD and related genetic disorders (e.g., fragile X syndrome and Rett syndrome). Many of these projects use animal and cellular models to explore the biological effects of specific candidate genes and to identify common molecular pathways, including alterations in synaptic functioning and intracellular signaling cascades.

Neural systems: Studies in this subcategory explore the structure and activity of the brain and underlying neural systems involved in autism, including functional connections between brain regions. Many projects seek to identify the precise neural networks underlying communication and language processing, social interactions, and behavioral issues. These studies frequently employ imaging techniques, such as functional magnetic resonance imaging (fMRI) and diffusion tensor imaging (DTI), and other physiological measures of brain activity, such as electroencephalography (EEG).

Neuropathology: These projects typically include post-mortem examination of brain tissue from ASD individuals. Many of the studies in this subcategory explore how the architecture of the brain may be altered in individuals with autism or how gene expression varies in different areas of the brain.

Sensory and motor function: Projects in this subcategory explore the neural underpinnings of motor skills and abilities in children with ASD and assess visual, auditory, and other sensory processes in the brain.

Subgroups/Biosignatures: Because there is so much heterogeneity among individuals with autism, research to understand how certain subgroups of individuals that share certain behavioral or biological characteristics could help understand some of the underlying biology in ASD. This can be done by searching for certain biological factors ("signatures"), such as hormone levels or structural abnormalities in the brain, that define a particular subgroup. Many of these projects try to make the connection between certain genes with a known or suspected link to autism and the observable characteristic, or phenotype, that they cause.

Question 3: Risk Factors

Environment: This subcategory includes a number of projects investigating potential environmental risk factors for autism. Example projects include studies of the effects of the microbiome, environmental contaminants and toxins, maternal dietary factors, medications taken during pregnancy or to induce labor, assistive reproductive treatments, child and maternal response to immune challenge, and registries where many of these factors can be tracked simultaneously.

Epigenetics: Epigenetics is the study of heritable changes in gene function that occur without a change in the DNA sequence (such as methylation of DNA). Environmental factors can cause these changes in gene expression, and projects in this subcategory seek to identify some of the environmental influences that may lead to these epigenetic changes.

Gene-Environment: These studies search for combinations of environmental risk factors and genetic susceptibility that increase the risk for ASD. (Note: While epigenetic studies often fit this definition, they are tracked separately for *Strategic Planning* purposes.)

Genetic risk factors: Projects in this subcategory seek to identify new genes that are implicated in increased risk for ASD or to better understand genetic risk factors that were previously identified.

Question 4: Treatments and Interventions

Behavioral: Projects in this subcategory involve a wide array of behavioral research and training methods, including applied behavior analysis (ABA), cognitive-behavioral therapy, discrete trial training, Early Start Denver Model, imitation training, joint attention training, Lovaas method, pivotal response training, sibling-mediated interventions, and social skills training.

Complementary, dietary, and alternative: This subcategory includes research on acupressure; acupuncture; antioxidants; cholesterol supplementation; glutathione metabolism; nutritional supplements, vitamins, and minerals; probiotics; and special diets (e.g., gluten-free, casein-free).

Educational: Nearly all research in classroom settings falls under this subcategory, including curricula, educational best practices, inclusive education programs, math and reading training, positive behavioral supports, special education programs, TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children), and the “Social Stories” approach.

Medical/Pharmacologic: This subcategory includes research on drugs (e.g., antidepressants, anticonvulsants, antipsychotics, anxiolytics, melatonin, and stimulants) to treat autism and its co-occurring conditions, as well as medical therapies such as transcranial magnetic stimulation (TMS).

Model systems/Therapeutic targets: Animal models mimicking behaviors of ASD and those that are being used to develop or test new drug treatments, as well as cell lines used to discover new drug targets or to screen potential drug candidates, are included in this subcategory.

Occupational, physical, and sensory-based: Therapies in this subcategory encompass art therapy, motor training (including fine motor skills such as handwriting as well as gross motor training involving balance and posture), music therapy, occupational therapy, pet (animal) therapy, physical activity plans and exercise therapy (bike riding, swimming), physical therapy, sensory integration, therapeutic horseback riding, training in self-care and daily living skills, and vocational rehabilitation.

Technology-based interventions and supports: Augmentative and alternative communication (AAC), computer applications and software, picture exchange communication system (PECS), social robots, teleconferencing, video modeling and virtual reality (including virtual and 3D environments to mimic social situations), and wearable sensors are all examples of the types of technology in the projects in this subcategory.

Question 5: Services

Community inclusion programs: These programs provide instruction in social, communication, and leisure skills to enable individuals with autism to participate in sports, recreation, and social-integration activities in fully integrated settings and to build successful relationships with others.

Efficacious and cost-effective service delivery: This subcategory includes programs involving web-based curricula and interventions as well as telehealth methodology, all of which could benefit those in underserved areas. Various parent training projects (to deliver a behavioral therapy, for example) using web-based methods such as teleconsultation and videofeedback make distributing the training programs cost-effective and accessible across the country. Studies to improve dental care are also in this subcategory for effective service delivery.

Family well-being and safety: Studies in this subcategory evaluate issues of caregiver stress and measures of quality of life for individuals with ASD and their families, as well as assess programs to help parents navigate the service system after their child receives an ASD diagnosis. It also surveys safety issues for those with autism, including wandering and bullying.

Practitioner training: Projects in this subcategory seek to increase skill levels in service providers, including medical providers, direct support workers, parents and legal guardians, education staff, and public service workers.

Services utilization and access: These projects include surveys of service systems available in different States, evaluations of patterns of medical service use among children with autism, a comprehensive online resource for autism services, and specific efforts in several States to coordinate services for people with autism. They also evaluate disparities in diagnosis and service utilization as well as barriers to access for racial and ethnic minorities.

Question 6: Lifespan Issues

Due to the small number of projects (34) and the significant overlap between topics covered in these projects, no subcategories were created for this question in the *2010 Portfolio Analysis Report*. As the research field grows, subcategories that encapsulate the scope of projects in this question may be defined in the future.

Question 7: Infrastructure and Surveillance

Biobanks: A biobank is a type of biorepository which stores human biological samples for use in research. Projects in this subcategory support collection of DNA and tissue samples from autism patients.

Data tools: These projects include bioinformatics databases to store genetic, phenotypic, and other medical information from autism patients. They also support infrastructure for several of these major databases to interact.

Research infrastructure: This subcategory includes coordinating centers that support multiple research projects by running tests, analyzing data, and providing statistical analyses. These projects also support facilities that operate large, shared instruments used by several scientists to test research samples.

Research recruitment and clinical care: Projects in this subcategory help increase participation in research studies and conduct medical evaluations for the participants, often collecting data that can be used for multiple studies.

Research workforce development: Workshops, conferences, and training programs that serve to expand the research workforce, enhance interdisciplinary research training, and recruit early-career scientists into the ASD field are included in this subcategory.

Surveillance and prevalence studies: Research that measures autism prevalence in the U.S. and internationally is contained in this subcategory, including the Autism and Developmental Disabilities Monitoring (ADDM) Network sites maintained by the Centers for Disease Control and Prevention (CDC).

APPENDIX C

NIH ARRA Initiatives

The table that follows lists the American Recovery and Reinvestment Act (ARRA) funding initiatives from the National Institutes of Health (NIH) that specifically mention autism or that funded autism research projects. For additional details, the announcement number can be searched at <http://grants1.nih.gov/grants/guide/index.html>. In the table, the “Activity Code” refers to the type of funding mechanism used to support the research projects (described in detail below the table).

Announcement Number	Release Date	Activity Code	Title
RFA-MH-09-170	03/23/2009	R01	Research to Address the Heterogeneity in Autism Spectrum Disorders
RFA-MH-09-171	03/23/2009	R01 collaborative	Research to Address the Heterogeneity in Autism Spectrum Disorders
RFA-MH-09-172	03/23/2009	R21	Research to Address the Heterogeneity in Autism Spectrum Disorders
RFA-MH-09-173	03/23/2009	R34 and R34 collaborative	Research to Address the Heterogeneity in Autism Spectrum Disorders
RFA-OD-09-003	03/04/2009	RC1	NIH Challenge Grants in Health and Science Research: 04-MH-101: Autism: Addressing the Challenge
RFA-OD-09-003	03/04/2009	RC1	NIH Challenge Grants in Health and Science Research: 05-MH-101: Leveraging Existing Healthcare Networks for Comparative Effectiveness Research on Mental Disorders and Autism
RFA-OD-09-003	03/04/2009	RC1	NIH Challenge Grants in Health and Science Research: 05-MH-103: Collaboration with AHRQ Comparative Effectiveness Research Program
RFA-OD-09-003	03/04/2009	RC1	NIH Challenge Grants in Health and Science Research: 05-MH-104: Building ASD Registries for Use in Comparative Effectiveness Research
RFA-OD-09-003	03/04/2009	RC1	NIH Challenge Grants in Health and Science Research: 08-MH-101: Beyond GWAS: Deep Sequencing of Mental Disorders
RFA-OD-09-005	3/30/2009	P30	Supporting New Faculty Recruitment to Enhance Research Resources through Biomedical Research Core Centers
RFA-OD-09-007	4/20/2009	R15	Academic Research Enhancement Award
RFA-OD-10-005	12/28/2009	RC4	NIH Director's Opportunity for Research in Five Thematic Areas

R01: Supports a research project in an area representing the specific interest and competencies of the investigator.

R21: Exploratory/developmental grant to encourage the development of new research activities.

R34: Provides support for the initial development of a clinical trial.

RC1: NIH Challenge Grants in Health and Science Research

P30: Supports shared resources and facilities for research by several investigators from different disciplines that focus on a common research area.

R15: Academic Research Enhancement Awards (AREA) that support small scale research projects primarily at undergraduate institutions.

RC4: Supports high impact research and research infrastructure programs.

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